Evaluation of the Macmillan Integrated Cancer Care Programme

Report of the evaluation findings
October 2018







Contents

1. Glossary of Terms	1
2. Executive Summary	3
3. Introduction	14
4. Evaluation methodology	28
5. Evaluation findings – progress and implementation	32
6. Evaluation findings – outcomes emerging	57
7. Evaluation findings – key learning emerging	75
8. Building the business case	79
9. Conclusions	86
10. Recommendations	91
11. Acknowledgements	96

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1. Glossary of Terms

This section provides a glossary of relevant terminology used throughout this report.

Term	Definition
Cancer Patient Partnership Group (CPPG)	The CPPG is a group of patients and carers who have used the cancer services and work with the Cancer Directorate Team at Addenbrooke's to improve patient and carer support along the whole cancer journey.
EPIC	EPIC is an integrated patient record, first developed in the USA and which connects different Addenbrooke's departments to a single system. A Doctor or Nurse looking at a patient's chart sees the full patient history, inputs their notes into it and uses EPIC to generate patient letters. Other departments input directly into EPIC, for example laboratory and radiology staff record test results and use it to trigger further referrals. At the point of the evaluation, the EPIC team were piloting an interface that would be sharable with GPs and other hospitals. Addenbrooke's first began implementation of EPIC in April 2012, going live in October 2014.
Macmillan Cancer Information and Support Service (MCISS) / POD	The MCISS / POD provides specialist information and support to all PABC. It allows medical / clinical staff to signpost patients to receive additional support regarding their medical condition and other concerns they may have. The MCISS / POD occupies a physical space and therefore is available for people affected by cancer and their carers to visit, to discuss any queries and concerns they may have.
MyChart	MyChart is an app for patients to access their patient record through EPIC and undertake the electronic Holistic Needs Assessment at home.
PABC	Person or people affected by cancer – within this report this term typically refers to cancer patients.
MICCP activities	
Risk stratification	Risk stratification refers to a process used by health and social care organisations to determine the type and level of need of a person as they go through a specific intervention. For Macmillan, risk stratification was one of the four key principles of aftercare drawn up in the National Cancer Survivorship Initiative.
	For the MICCP, risk stratification of PABC was a tool to shape appropriate follow-up care through Nurse-led clinics ¹ .
Recovery Package	The Recovery Package is a core component of the Survivorship Agenda, designed to meet the challenges of the increased numbers of survivors of cancer, to help people identify and tackle their concerns so that they can better self-manage after their treatment ends.
	The Recovery Package is recognised in the NHS England Five Year Forward View and the Cancer Taskforce Strategy, and consists of four main interventions: Holistic Needs Assessment (HNA) and Care Planning, Treatment Summary, Cancer Care Review and Health and Wellbeing Events ² .
Recovery Packag	e Elements
eHNA	eHNA (electronic Holistic Needs Assessment) is an electronic assessment that identifies a PABC's practical, physical, emotional, spiritual and social needs. It can be conducted through an iPad or computer either in the hospital or at the PABC's home.

 $^{^1}$ For more information about the role of risk stratification in the NCSI see <u>Care After Cancer</u> (2009), Macmillan and Southampton University report.

² For more information about the Recovery Package, visit the <u>Recovery Package</u> page on Macmillan's website.



1

Term	Definition	
Care Plan	A Care Plan records the needs that are most important to that person at that time. It should be shared with the person and other health and social care professionals so it can be enacted. It also provides the foundation for future re-assessment and re-planning, as a person's holistic needs can change along the pathway.	
Treatment Summary	A Treatment Summary is a document (or record) completed by secondary care professionals, after a significant phase of a PABC's treatment. It describes the treatment, potential side effects, and signs and symptoms of recurrence. The Treatment Summary aims to inform the GP and other primary care professionals of actions that need to be taken and who to contact with any questions or concerns. The PABC also receives a copy to improve their understanding, including regarding anything to look out for during their recovery ³ .	
Exercise Referrals	Exercise Referrals are the method in which patients are referred to exercise activities. This can be through the MCISS.	
Health and Wellbeing Event (HWB)	HWB events are designed to help people affected by cancer and their family and friends get the support they need during and after cancer treatment. Health and Wellbeing Events provide information and support on:	
	Benefits and other financial support	
	How to get back to work	
	Diet and lifestyle	
	Long-term side-effects of treatment	
	Local services.	
Rehabilitation and Exercise during Addenbrooke's	REACT was not directly funded by MICCP (although it did secure funding with MICCP support) but the REACT and MICCP team worked together to identify and streamline an Exercise Referral system for PABC.	
Cancer Treatment (REACT)	REACT offers more than just exercise. Rather than focus on an individual problem it looks at the holistic needs of the PABC; for example, not just the muscle wastage of a Prostate cancer patient but whether that person has pelvic floor/balance issues and whether their bone health is suffering.	
	Source: SOW	

Source: SQW

 $^{^{3}}$ For more information about Treatment Summaries see the $\underline{\text{Macmillan website}}.$



2. Executive Summary

The Macmillan Integrated Cancer Care Programme

The Macmillan Integrated Cancer Care Programme (MICCP) at Cambridge University Hospitals Foundation Trust (CUHFT) is funded by Macmillan Cancer Support (Macmillan) and delivered primarily at Addenbrooke's Hospital. The programme began in 2015 and Macmillan funding ends in December 2018. The programme aims to change and improve cancer care by risk stratifying pathways of care for people affected by cancer (PABC) and by embedding elements of the Recovery Package within Addenbrooke's – specifically, electronic Holistic Needs Assessments (eHNA) and Care Plans, Treatment Summaries, Exercise Referrals and Health and Wellbeing (HWB) events.

The MICCP has been delivered across four main programme workstreams: the Patient (Recovery Package and risk stratification), Staff (culture change), Infrastructure, and Integration.

The MICCP evaluation

This study was commissioned to provide an independent formative, summative and economic evaluation of the MICCP, generating context-specific insights and learning to inform future sustainability as well as any potential roll-out and scaling of the programme.

The study involved the design and development of a programme level and three cancer site-specific theory of change (ToC) models; an evaluation framework; and capturing primary and secondary data in order to generate key insights. The evaluation ran from May 2017 to June 2018, concurrent with MICCP implementation during this period.

Why integrate cancer care?

The MICCP was a direct response to the rising demand for cancer care and the wider policy context.

Rising demand for cancer care: The population projections for people living in East Anglia and the NHS Cambridgeshire and Peterborough area are increasing year on year⁴. Over the past 20 years, the number of registrations for newly diagnosed cases of cancer in England increased by approximately 70%, from 288,000 in 1995 to 490,000 in 2015⁵. Patient numbers at CUHFT continue to increase, with a predicted increase of 7% per year within the Cancer Directorate moving forwards. The number of PABC receiving follow up care also continues to grow, with over 8000 patients attending follow up appointments in 2016⁶.

The policy context: The NHS Five Year Forward View⁷ (2014) identified new models of integrated care, whilst acknowledging that services needed to be designed locally to meet local needs. The national cancer strategy, Achieving World-Class Cancer Outcomes⁸ (2015) was published in response to the NHS Five Year Forward View. In 2013 the National Cancer Survivorship Initiative

⁸ Achieving World-Class Cancer Outcomes: A strategy for England 2015-2020



3

⁴ Population Statistics Division, Office for National Statistics (2014)

⁵ Cancer Registrations Statistics, Office for National Statistics (2015)

⁶ Taken from CUHFT's report, Division B – B4: Living with and Beyond Cancer Service: to deliver risk stratified care and the Recovery Package

⁷ The NHS Five Year Forward View (2014) and other documents can be downloaded from the NHS website.

published their report, Living with and Beyond Cancer: taking action to improve outcomes⁹. This report was designed to inform the direction of survivorship work in England until 2015. It provided evidence to encourage commissioners and providers around the type of services required for cancer survivors in order to deliver improved outcomes.

The MICCP vision

The MICCP is an ambitious programme of work, particularly given the size of Addenbrooke's and the role of CUHFT as a tertiary referral centre, and not to mention the general pressures facing the NHS with a growing and ageing population. As the MICCP began early implementation, the complexity of delivering a transformation programme consistently across all 23 cancer sites in Addenbrooke's became apparent. The MICCP team re-assessed the programme vision and scope to reflect this operating context

The early implementation phase required intensive engagement from a wide range of stakeholders across the cancer workforce. Between 2015 and 2018 the programme team targeted their support at specific cancer pathways, in a pragmatic approach to integrate cancer care effectively in pockets of activity. They built tools, capabilities, understanding and best practice, to engage new cancer sites and enable integrated cancer care to become 'business as usual' in future.

Evaluation findings – progress and implementation

Integrating cancer care across the four MICCP workstreams was not a linear process. Implementation of different MICCP activities varied both between and within individual cancer sites. Staff and volunteer involvement and IT infrastructure builds happened in fits and spurts, depending on competing demands. A planned and pragmatic approach was taken, to maintain momentum with implementing the MICCP in the fast paced and complex operating environment of Addenbrooke's Hospital.

Workstream 1 - Patient: Risk stratification

The MICCP team's **initial aim was to risk stratify all 23 cancer sites**, but a strategic decision was taken to prioritise early implementation of risk stratification in sites with the greatest potential to achieve early success. By March 2018, a **total of 20 pathways were mapped and risk stratified** across all cancer sites. Risk stratification involved moving patients from a consultant led clinic to a nurse led clinic. Low Grade Prostate clinics were led by both Nurses and Allied Health Professionals (AHPs). Clinics were undertaken in a variety of formats: telephone-based, face to face and holistic, depending on where they occurred within the pathway.

Risk stratification requires relevant clinicians at the sites to collaborate to make shared-decisions around patient care. As a result, **maintaining momentum was often a challenge**, particularly when a key member of staff left, and their replacement brought different expertise and experience to the whole process. At these points the MICCP team intervened to help identify a shared solution. To achieve engagement at cancer site level, the Cancer Nurse Specialist (**CNS**) and Allied Health **Professional (AHP) workforce were key.** The MICCP team supported Senior CNS team leads who

⁹ Living With and Beyond Cancer: Taking Action to Improve Initiatives (2013) National Cancer Survivorship Initiative



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acted as the clinical 'champions' at site level, encouraging colleagues to engage and maintain momentum.

At each point, the progress of risk stratification and setting up new clinics was affected **by capacity issues at Addenbrooke's**. Additionally, **every cancer pathway is different**, with different staff, capacity and culture, so there was no 'one size fits all' approach.

Workstream 1 - Patient: The Recovery Package

The electronic Holistic Needs Assessment (eHNA): The most widely-delivered element of the Recovery Package was the eHNA, with 843 eHNAs taking place. There was a significant increase in the number of eHNA consultations that took place between 2015 and 2016. This was partly due to aligning eHNA completion with staff development objectives to motivate their engagement. PABC agreed that the eHNA was a valuable tool supporting different conversations with clinicians. Divergent views persist regarding the best timing for the intervention however.

Care Plans: There were 666 Care Plans generated between November 2015 and November 2017. Stakeholders agreed that Care Plans were useful for PABC, particularly in providing contact details for different queries or concerns; and detailing symptoms to look for. As such, they were welcomed as a highly beneficial tool in supporting PABC to self-manage and take control over their care. Interviewees however pointed out a number of ways in which the usability of the Care Plans could be improved, particularly in terms of functions that would speed up their completion.

Treatment Summaries: Treatment Summary activity was trialled in one case study site – Colorectal – which worked to design and test a tailored template for that site. This site was strategically selected due to its senior stakeholder support. Stakeholders agreed that Treatment Summaries could be useful in supporting self-management during recovery.

Exercise Referrals: Referrals to two exercise schemes were seen as key successes of the MICCP. This included the REACT programme delivered by a CUHFT Senior Physiotherapist and a scheme delivered through a partnership built up with Cambridgeshire County Council. The MICCP team created and streamlined processes to enable the cancer workforce to refer PABC for Exercise Referrals. PABC feedback regarding the Exercise Referral schemes was extremely positive.

Health and Wellbeing Events: Two events took place, one in 2015 and one in 2016. The events were deemed to be successful, but the preparation and delivery were resource intensive. Additionally, the multiple partners involved had different priorities for the events, which didn't always align.

Workstream 2: Workforce and culture change

The second MICCP workstream **focused on workforce development**, **with the longer-term objective of achieving culture change**. The MICCP team designed a **Learning and Development programme** to be delivered to the workforce within the CUHFT Cancer Directorate. The content of the training was evidence based and focussed on empowering the individual. It aligned with a wider drive towards person-centred approaches within the NHS Five Year Forward View and CUHFT's Learning & Development Strategy.

The training was advertised to all staff groups (qualified and non-qualified, including medics) across all cancer sites. The majority of participants were from nursing and AHP roles; no medics



attended. Three one-day training courses on Self-Management Support were held for staff in May, June and October 2017, and a total of 21 staff members attended one of these courses.

Workstream 3: IT systems

Workstream 3 was designed to encompass a range of changes to the IT infrastructure, to facilitate an improved flow of information across cancer services. Whilst the CUHFT EPIC team did support a number of builds for the MICCP, **securing EPIC team time emerged as a persistent barrier to delivery of the MICCP**. Changes to IT took significant time to be approved, followed by a secondary lag before implementation. There remain several outstanding requests logged but not yet approved, for example the functionality to extract data on the use of Treatment Summaries. This has led to **staff frustrations**. However, there were multiple reasons for the delays to EPIC builds. Work to tailor EPIC was an ongoing exercise, and the bi-annual EPIC upgrade meant that the new functionality and technology was constantly being adapted to the needs of the Trust.

Systemic delays to implementing EPIC IT builds had a significant knock-on impact on the MICCP team's ability to progress certain aspects of the Recovery Package, such as uploading Treatment Summary templates or being able to extract data to monitor and analyse implementation progress.

Workstream 4: Partner engagement

Workstream 4 was set up in recognition that **whole-system change cannot happen within secondary care alone**. As such, the MICCP included a workstream to engage wider partners across the cancer workforce, including GPs, the voluntary and community sector, Cambridgeshire County Council and other strategic stakeholders including the Cancer Alliance and CCG. Workstream 4 implementation focused on wider **GP engagement**.

The impact of the MICCP

For people affected by cancer

The MICCP sought to increase the number of opportunities for PABC to express their needs, improve the quality of conversations, provide tailored information and improve the overall experience of care. The MICCP:

- Gave PABC the opportunity to express their needs: the Recovery Package toolkit was reported by stakeholders to provide PABC with the opportunity to express their holistic needs.
- Supported PABC to have new and different conversations through use of the eHNA: PABC interviewees described how the thematic topics explored via the eHNA from spiritual, financial, to mental health and fitness prompted them to think about and recall different concerns that they might not have otherwise felt were relevant to mention. Even those PABC who considered themselves particularly capable of finding their own information and were well-supported by family and friends described ways in which the eHNA provided the opportunity to access different information.



- **Supplied information to help PABC to self-manage:** stakeholders were broadly positive that the Recovery Package toolkit supported PABC to self-manage by giving them relevant information, including information around diet and nutrition, sleeping issues, worries over the genetic properties of cancer and side effects of treatment.
- Improved the overall PABC experience: PABC appreciated the opportunity to discuss non-clinical concerns in the hospital setting. This was best summarised by one PABC who otherwise felt that she needed little additional support but who felt that the eHNA helped to 'validate her as a person, beyond being part of the machine of oncology', shifting the focus away from cancer and back to them as a whole person.
- **Provided follow up care which PABC found to be more convenient and less stressful:**PABC interviewees who experienced telephone, Nurse-led follow up appointments identified several benefits to the risk-stratified clinics, including saving time and money by reducing the number of hospital visits, and reducing the emotional burden associated with attending the hospital. PABC surveys after follow-up clinics showed highly positive responses to all key indicators of patient experience.

For the cancer workforce

By supporting staff and volunteers (primarily through tailored training courses), the MICCP worked to equip a core of the cancer workforce with the tools and competencies needed to deliver new models of care. Training evaluation forms asked the workforce to reflect on whether (and the extent to which) the training had altered their attitudes and beliefs when delivering cancer care. The responses (from the Self-Supported Management course) were overwhelmingly positive, with attendees reporting the training to be 'mind altering.' The MICCP:

- Encouraged training attendees to re-evaluate their relationships with PABC, so that the PABC set the agenda and took ownership of their own plans. Training participants also explored the specific skills required to have new conversations, for example how to phrase questions and consider the situation from the PABC's point of view.
- Built the knowledge, skills and confidence of the workforce. Pre- and post-training questionnaires explored the extent to which the Self-Supported Management training had a positive impact across 13 indicators. All indicators showed a notable increase in workforce self-assessment of confidence, skills and knowledge after the training.
- Encouraged the new skills to be put into practice. Trainees described the different ways
 they anticipated the training to impact upon their practice, for example how it would shape
 the way they set the agenda for consultations, encouraging greater use of open questions.

Whilst stakeholder interviewees were broadly positive about their abilities to put the training into practice, they did outline some **barriers** to doing so. These included **workloads**, **constrained staffing levels and entrenched ways of working**.

For cancer services

The MICCP embedded a wide range of new processes and systems to improve the overall structure and effectiveness of cancer services at Addenbrooke's Hospital. The MICCP tackled processes ranging from reworking the template for new patient clinics, setting up Exercise Referral processes,



to informing new system builds within EPIC. Alongside this sat the workforce development plan, upskilling a core of the cancer workforce with the knowledge, skills and confidence to lead a shift in culture, with PABC as partners in their care.

Measuring the impact of the MICCP upon cancer services is challenging given the complexity of the system and other factors affecting service operation. Nonetheless, the MICCP led to:

- Improved coordination of patient pathways. Interviewees described how the MICCP had improved the coordination of PABC pathways in a number of ways, including: Nurse led clinics meant that low-risk cohorts of PABC received more appropriate follow-up care; Exercise Referrals followed a streamlined process; Recovery Package elements such as eHNA and Care Plans on EPIC improved cancer workforce awareness of PABC journeys; and eHNA conversations enabled effective signposting to information to meet PABC needs.
- Improved relationships between PABC and healthcare and support services. PABC were positive about the impact of the eHNA on their relationships with Addenbrooke's staff, and how this differed to their previous experiences of cancer care. PABC on five-year check-ups reported how the eHNA was their first opportunity to speak to a member of the cancer workforce about wider concerns, and welcomed these conversations, feeling that they were treated as individuals.
- **Improved capacity across the system.** Risk stratification of PABC 'freed up' senior clinician time, which was critical for accommodating newly diagnosed PABC. Risk stratified follow-up care, whilst time consuming for everyone involved in pathway mapping, was well received and valued by healthcare professionals and PABC.

For the cancer system

Specific areas of successful engagement include:

- The Exercise Referral process, which encouraged neighbouring local authorities to employ instructors, supporting greater numbers of PABC.
- The MICCP team influenced strategic partners, leading to greater clarity amongst key stakeholders about MICCP activities.
- The Macmillan GP was involved in designing and trialling the Treatment Summary at the Colorectal site, which informed a template for wider roll out to other cancer sites.

Key learning: maintaining momentum

The evaluation identified five ways in which the MICCP team maintained momentum in the complex and ever-changing operating context of a busy tertiary hospital:

- 1. **Prioritisation of quick wins:** By prioritising who to work with, where to work and the specific area(s) of focus, the MICCP trialled and tested activity, generating ongoing learning to inform wider roll out.
- **2. Adopting a fluid approach:** The MICCP team was able to quickly re-prioritise and change focus, depending on momentum and capacity at that particular moment.



- **3. A project team with a 'can do' approach:** Recognising the pressures and competing priorities facing key stakeholders, the MICCP team took on a variety of tasks to support implementation, from basic administration through to high level influencing.
- **4. Influencing:** The MICCP team networked through formal channels within Addenbrooke's, whilst also networking externally, attending meetings with the Cancer Alliance, Macmillan GP and CCG. The dedicated MICCP team effectively encouraged engaged stakeholders, such as CNSs, to champion the work within and across sites.
- **5. Be realistic about the pace of change:** The wider delivery context meant that the MICCP team revised their expectations of what was possible within the 3-year programme. Being realistic about the pace of change and recognising the scale of the challenge was vital in managing wider stakeholder expectations.

Specific areas of learning

As well as the behaviours and broader approach outlined above, the evaluation reveals other learning to consider when integrating cancer care. These include:

- The importance of **engaged clinicians with the authority, capacity and skills needed** to unite and enthuse colleagues around a shared vision and new ways of working.
- The role that **volunteers** can play in providing low level non-complex support.
- The importance of a **Macmillan GP champion** to trial and test specific elements and to disseminate information in an appropriate way to other GPs, providing peer credibility and understanding of the context in which they operate.
- Ensuring a **fully resourced programme team** across the whole period of delivery, able to pick up different levels of activity across multiple cancer sites and stakeholder groups.
- **Prioritising and trialling new ways of working on a site by site** basis, rather than attempting to drive through all activities at the same time.
- Collecting meaningful PABC experience data at every opportunity where appropriate e.g. risk stratified clinic feedback, to inform revisions and refinement to the model.
- **Consider IT implications and build these into the work plan,** specifically in terms of prioritising activities or workstreams that will help to generate 'quick wins'.

Building the business case: the economic evaluation

The economic assessment uses information from the risk stratification and re-design process as recorded in CUHFT's Change of Methodology Recordings (CMR), along with programme budget data provided by Macmillan. The assessment includes details of costs needing to be picked up after the end of the Macmillan funding, in order to continue the Recovery Package and sustain the savings in the pathways. As the MICCP is still in delivery, the economic assessment includes an estimate of the, as yet, un-identified savings – e.g. anticipated savings that have yet to be realised. For example, this includes clinics to be commissioned during the remaining programme and beyond. The



assessment includes scenarios to explore potential variations in the scale of the un-identified savings, with optimism bias set at $5\%^{10}$ in the CMR estimates¹¹.

In all scenarios except the low assessment (without any assumed efficiency savings) the return on investment (ROI) is over 1.0, with payback period of 5-6 years. For the low scenario with no efficiency savings there is a small budget impact of £30,804 (this is the additional budget required to finance the programme under this scenario).

Table 1: Economic assessment of the three scenarios

Metric	Low	Medium	High
With no efficiency savings			
Net Present Budget Impact	£30,804	-£210,719	-£452,242
Overall Financial Return on Investment	0.99	1.08	1.16
Payback period	-	6 years	5 years
With efficiency savings of 5% p/a ¹²			
Net Present Budget Impact	-£453,850	-£745,866	-£1,037,882
Overall Financial Return on Investment	1.16	1.27	1.37
Payback period	6 years	5 years	5 years

Source: - SQW economic assessment calculations.

The number of patients attending the CUHFT Cancer Division increases annually, and the modelling includes an assumed 7% growth in activity per annum. **If the MICCP was not implemented, the current costs would continue to grow year-on-year in line with patient numbers**. As such, by risk stratifying new patient pathways through the MICCP, the Trust is helping to meet rising demand and mitigate against the associated cost and resource implications of caring for a growing population of PABC.

However, the full extent of the benefits and costs associated with the MICCP will not emerge for several years yet. It is important to note that these calculations do not include wider potential benefits and costs, for example those for PABC or upon the wider cancer care system.

Conclusions

The MICCP is a key part of the wider strategy to improve cancer care and coordinate pathways, but there remains work to do at cancer site, service and system levels. The funding provided to sustain the programme post-December 2018 (following the end of Macmillan's funding) indicates the value placed by local commissioners on the new ways of working. Embedding the model as 'business as

¹² It is anticipated that once clinicians and PABC feel comfortable with pathways and the new ways of working become embedded, efficiency savings can be realised.



10

 $^{^{10}}$ Optimism bias can provide a correction for the uncertainty around the available evidence, through an increase in the programme costs and a decrease in the financial value of identified benefits.

¹¹ Data on risk stratification and attendances where the CMRs have been implemented may help assess the robustness of

usual' offers potential for further benefits to emerge as the ways of working are sustained and further rolled out.

The Macmillan-funded three-year programme has enabled the trialling and testing of new ways of working, to understand and address the barriers, and build on the enablers. Whilst the pace of change has at times proved frustratingly slow, the risk stratified pathways continue to become live and momentum grows. The MICCP provides the foundation on which the programme can build under 'business as usual' delivery moving forwards.

Recommendations for local commissioners and the Cancer Alliance

Recommendation 1: Adopt a whole-system perspective to cancer care commissioning, to maximise impacts. For example, consider financial implications across partners. This can help generate their buy in and maintain programme momentum.

Recommendation 2: Recognise risk stratification and Recovery Package activity not as a means to generate immediate savings, but as a means to meet the challenges of increasing demand for cancer care. This evaluation has shown that the model does offer potential to help meet rising demand.

Recommendation 3: Be realistic about the expected scale and pace of change, given the system-wide focus of the MICCP. Understand that every pathway is different and that it takes time to build the necessary clinical and workforce engagement to maintain momentum around risk stratification.

Recommendations for CUHFT

Recommendation 4: Consider recruiting a formal clinical 'champion' to act as a high-level influencer across sites, to unblock barriers and maintain momentum. Additionally, use existing 'champions' to communicate the benefits and encourage other sites to integrate cancer care.

Recommendation 5: Hold a strategic meeting with senior executives to discuss and prioritise the IT infrastructure required to support risk stratification and Recovery Package implementation.

Recommendation 6: Consider how best to engage local GPs so they are ready for Treatment Summaries and are sufficiently knowledgeable about the Recovery Package, utilising the Macmillan GP's networks and expertise for support.

Recommendation 7: Engage internal and external commissioners to explore ways to minimise internal commissioning delays. Develop a schedule for anticipated CMRs to agree with the relevant director, in order to minimise delays and mitigate against issues if delays do occur.

Recommendation 8: Continue with the training for the workforce. Given the need to generate culture change at site level, consider delivering team-based or 'train the trainer' programmes, and target medics who play important roles in department culture by flexing times to suit them.

Recommendation 9: Use Care Plans to support continuity of care for patients when they are transferred between departments i.e. Oncology and Urology. Supporting practitioners in the sites to correctly use the IT system that underpins the Care Plan process will be key to this.



Recommendation 10: Continue the roll out of risk stratification within high priority sites, which can be selected either for their national strategic importance or for MICCP strategic importance (e.g. to trial a new form of clinic or risk stratify remaining pathways at engaged sites).

Recommendation 11: Consider which elements of Recovery Package implementation should be standardised, and which can be flexed, e.g. flexibility for PABC to complete the eHNA at home, or varying the timing of the eHNA on a site-by-site basis.

Recommendations for Macmillan

Recommendation 12: Consider how best to engage local GPs to help ensure they are ready for Treatment Summaries to be introduced more widely, and are sufficiently knowledgeable about the Recovery Package. This may be through a phased implementation via the Macmillan GP's networks.

Recommendation 13: Continue to maintain and strengthen relationships with the CCG and Sustainability and Transformation Partnership, to help to build their understanding of MICCP and inform their priorities for future commissioning.

Recommendation 14: Continue to share learning emerging from elsewhere regarding the Recovery Package or components of the MICCP (e.g. eHNA, Treatment Summaries etc.) to inform refinement of the model in Addenbrooke's, and/or inform roll-out to other sites.

Recommendation 15: Consider delivering Health and Wellbeing events at a regional level, rather than events being delivered by the Trust. There may be economies of scale through a regional approach, which Macmillan could usefully play a key role in.

Recommendation 16: The administration of eHNA was complicated by the introduction of new Macmillan administration steps. In future it may be useful to work with Trusts before introducing IT changes which affect day to day operational activities, possibly trialling new ways of working.

Recommendations for others seeking to replicate the MICCP model

Recommendation A: Ensure resource requirements have been thought through e.g. a dedicated programme team with the necessary capacity and capability to undertake a wide range of activities, from strategic engagement and influencing, to mentoring and administrative support.

Recommendation B: Explore IT, information governance and monitoring requirements at an early stage, and secure buy-in from the IT support team (and others). In addition, agree at the outset (as far as possible) exactly what monitoring data is required to meet commissioner needs.

Recommendation C: Focus early activity on achievable sites and activities. These are likely to be those cancer sites with the capacity, capability and physical space to conduct risk stratification activities and embed the Recovery Package. Starting small and achieving quick wins can help to generate enthusiasm, momentum and learning to support wider roll out.

Recommendation D: Be mindful that risk stratification can be a lengthy process and that external factors may adversely affect progress or momentum. It is vital to manage expectations and be realistic about the anticipated pace of change, building in contingencies where needed.



Recommendation E: Build in evaluation and PABC engagement at the outset. Collect meaningful qualitative and quantitative PABC experience data where appropriate e.g. gathering risk stratified clinic feedback, and use this in a structured way to inform revisions and refinement to the model.

Recommendation F: Align integration with the wider Cancer Alliance and national cancer strategy. Strategic alignment will be key to securing funding and buy in. Engaging senior champions to position integration as an integral part of the local strategy may also help to raise the profile of the programme and ensure implementation is prioritised.

Recommendation G: Gain broader 'on the ground' awareness by identifying and supporting clinical champions who can influence and persuade colleagues to engage. Clinical champions offer credibility amongst their peers that can prove key to securing buy in.

Recommendation H: Plan for sustainability at the outset. This is vital to avoid the new ways of working being seen as 'just another initiative' and to help overcome any change fatigue. Engaging with commissioners will be vital to supporting sustainability.

Recommendation I: Link Recovery Package and risk stratification activities into staff development plans, e.g., the use of eHNA or Care Plans, and/or attending training. This can all contribute towards culture change and sustaining the impacts of the model in future.

Recommendation J: Implement a tailored learning and development programme alongside the new care pathways, to embed the new ways of working. This could usefully focus on building a trusting, open relationship between PABC and the cancer workforce, encouraging culture change. Targeting the early implementers of the model for the first waves of training will help to ensure the ways of working align with the new pathways.



3. Introduction

The Macmillan Integrated Cancer Care Programme

The Macmillan Integrated Cancer Care Programme (MICCP) at Cambridge University Hospitals Foundation Trust (CUHFT) is funded by Macmillan Cancer Support (Macmillan) and delivered primarily at Addenbrooke's Hospital. The programme began in 2015 and Macmillan funding ends in December 2018. The programme aims to change and improve cancer care by risk stratifying pathways of care for people affected by cancer (PABC) and by embedding elements of the Recovery Package within Addenbrooke's – specifically, electronic Holistic Needs Assessments (eHNA) and Care Plans, Treatment Summaries, Exercise Referrals and Health and Wellbeing (HWB) events.

The dedicated MICCP team is based within the Cancer Directorate and linked with other areas across the wider Trust where cancer care is delivered, e.g. the Surgical Directorate, Physiotherapy Services, Dietetics, and with those who provide psychosocial support, such as the Macmillan Cancer Information and Support Service (MCISS) and Chaplaincy. Changes to services are coproduced with PABC and members of the Cancer Patient Partnership Group (CPPG). PABC representatives sit on the programme steering and implementation groups, alongside CUHFT staff and other stakeholders.

The MICCP has been delivered across four main programme workstreams, specifically:

- 1. Patient (Recovery Package and risk stratification)
- 2. Staff (culture change)
- 3. Infrastructure
- 4. Integration.

The national context

Rising demand for cancer care

The population projections for people living in East Anglia and the NHS Cambridgeshire and Peterborough area are increasing - with a 16% and 20% projected rise from 2014 to 2038 for each area respectively 13 . In the past 20 years, the number of registrations for newly diagnosed cases of cancer in England increased by approximately 70%, from 288,000 in 1995 to 490,000 in 2015^{14} . Age standardised rates have also increased over time.

Patient numbers at CUHFT continue to increase year-on-year. With around 4,000 new cancer patients each year (2015/16), and a predicted increase of 7% per year, the number of PABC

¹⁴ Cancer Registrations Statistics, Office for National Statistics (2015)



14

¹³ Population Statistics Division, Office for National Statistics (2014)

receiving follow up care also continues to grow, with over 8000 patients attending follow up appointments in 2016^{15} .

The following table shows the steady increase in the number of registrations for newly diagnosed cases of cancer in England between 1995 and 2015. Within Addenbrooke's the number of people diagnosed with cancer per year has risen to 11,019 in 2017. This indicates the growing demand for cancer care, which in turn has significant resource implications for the Trust.

 $^{^{15}}$ Taken from CUHFT's report, Division B – B4: Living with and Beyond Cancer Service: to deliver risk stratified care and the Recovery Package



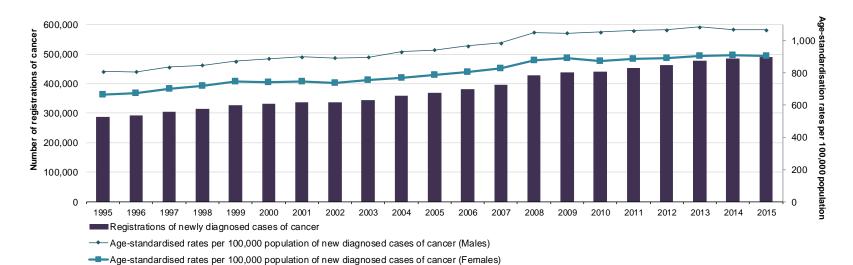


Figure 3-1: The number of registrations for newly diagnosed cases of cancer in England

Source: Cancer Registrations Statistics, Office for National Statistics (2015)



The policy context

The NHS Five Year Forward View¹⁶ (2014) identified new models of integrated care, whilst acknowledging that services needed to be designed locally to meet local needs. The national cancer strategy, Achieving World-Class Cancer Outcomes¹⁷ (2015) was published in response to the NHS Five Year Forward View. It focused on six major domains:

- Spearhead a radical upgrade in prevention and in public health
- Drive a national ambition to achieve earlier diagnosis
- Establish patient experience on a par with clinical effectiveness and safety
- Transform the approach to supporting people living with and beyond cancer
- Make the necessary investments required to deliver a modern, high quality service
- Ensure commissioning, provision and accountability processes are fit for purpose.

One of the key elements of the National Cancer Strategy was the development of Cancer Alliances. Cambridge sits at the centre of the East of England Cancer Alliance, which comprises all of Norfolk, Suffolk, Cambridgeshire, Essex, Hertfordshire and Bedfordshire. This is the largest Cancer Alliance in the country, covering a population of over six million people.

In 2013 the National Cancer Survivorship Initiative (NCSI) published their report, Living With and Beyond Cancer: taking action to improve outcomes¹⁸. This report was designed to inform the direction of survivorship work in England until 2015. It provided evidence to commissioners and providers around the type of services required in order to deliver improved outcomes.

CUHFT's Strategy for Cancer Services (2017-22)¹⁹ built upon these national and local strategies to outline the following goals:

- To improve outcomes for patients with cancer
- To improve patient experience
- To deliver a sustainable service
- To accelerate Cambridge science into the clinical setting.

The CUHFT strategy identified **integrated cancer care** – specifically risk stratification of cancer pathways and targeted elements of the Recovery Package – as a key workstream.

The MICCP aligns with the policies at a local and national level, and was a response to:

- The clear focus of the National Cancer Strategy on prevention and early detection
- The NCSI agenda and evidence base for improving PABC outcomes and experience

¹⁹ Cambridge University Hospital NHS Foundation Trust Strategy for Cancer Services 2017-22



¹⁶ The NHS Five Year Forward View (2014) and other documents can be downloaded from the NHS website.

¹⁷ Achieving World-Class Cancer Outcomes: A strategy for England 2015-2020

¹⁸ Living With and Beyond Cancer: Taking Action to Improve Initiatives (2013) National Cancer Survivorship Initiative

• CUHFT's focus on patient outcomes, patient experience and sustainability, particularly to respond to the challenge of meeting increased local demand for cancer care.

The MICCP vision

The MICCP is an ambitious programme of work, particularly given the size of Addenbrooke's and the role of CUHFT as a tertiary referral centre, as well as the general pressures facing the NHS with a growing and ageing population. Initial scoping plans from 2015 illustrate the vision of MICCP as a transformation programme within Addenbrooke's:

"This project aims to transform the way in which services are delivered, moving away from a medical model to a more holistic approach, working in partnership with patients to co-produce services that are sustainable and fit for purpose...

"Organisational change [will lead to] a culture that enables and empowers both patients and staff, assisted by development of a health coaching model to support patients to work in partnership with healthcare providers rather than becoming recipients of care."²⁰

The MICCP was structured across four workstreams. As the MICCP began implementation, the complexity of delivering a transformation programme across all 23 cancer sites in Addenbrooke's became clear. The MICCP team re-assessed the programme vision in response.

Between 2015 and 2018, the MICCP team engaged with individual members of the workforce as part of a pragmatic approach to integrate cancer care in specific CUHFT cancer sites. The team scaled back the initial plan to work across all 23 cancer sites, and instead focused effort primarily on those sites and activities with the greatest readiness to engage, in order to generate learning and momentum. This was with a view to embedding risk stratification and the Recovery Package as 'business as usual' within cancer sites in the Trust longer term.

Integrating cancer care requires significant resources and effort, with many of the benefits expected to be realised over the longer-term. By working with a smaller number of sites, the MICCP team was able to build and test the tools, capabilities, understanding and best practice required to motivate further cancer sites to engage with the programme. In many ways, the three years of the MICCP can be viewed as the 'pump priming' phase of integrating cancer care at Addenbrooke's.



Table 3-1: Overview of the originally planned four MICCP workstreams

The patient – survivorship, risk stratified care, the toolkit	Infrastructure
 eHNA / EPIC²¹ HNA Treatment summaries Care Plans Psychological services/support Exercise and lifestyle programs Pre and Post Treatment events Referral processes Nurse-led services/ Allied Health Professionals Wellbeing Events Patient Information SOS pathway 	 Remote Consultations CUH Direct EPIC interface Tools - patient portal, apps etc. Website IT interface with community Governance Communications
Staff – culture change	Integration
 Personnel development Organisational change Training Education Guides - How to implement Information Events 	 General Practitioners (GPs) Community Services Third sector Volunteers Education and Training events Cancer Community Nurses

Source: MICCP evaluation specification, March 2017



Introduction to the MICCP evaluation

This study was commissioned to provide an independent formative, summative and economic evaluation of the MICCP, generating context-specific insights and learning to inform future sustainability as well as any potential roll-out and scaling of the programme.

The study involved the design and development of a programme level and three cancer site-specific theory of change (ToC) models. These informed development of an evaluation framework, and primary and secondary data collection. The evaluation ran from May 2017 to June 2018.

The evaluation explored the strategic alignment of the programme, exploring differences and commonalities across three cancer sites in-depth, as well as at a programme level. The study explored partner involvement and relationships, the success factors and challenges/barriers experienced, and the implications of the learning.

Formative insights have been shared with the MICCP team throughout the study, via a Baseline Report, an Interim Report and fortnightly update call.

Exploring three sites in-depth

Three cancer sites - Breast, Colorectal and Prostate – were explored in-depth within the evaluation. These sites were selected in discussion with Evaluation Steering Group members and are strategically important: all three sites are East of England Cancer Alliance priorities and have the biggest patient volumes. These three sites have also seen some of the greatest progress through the MICCP to date.

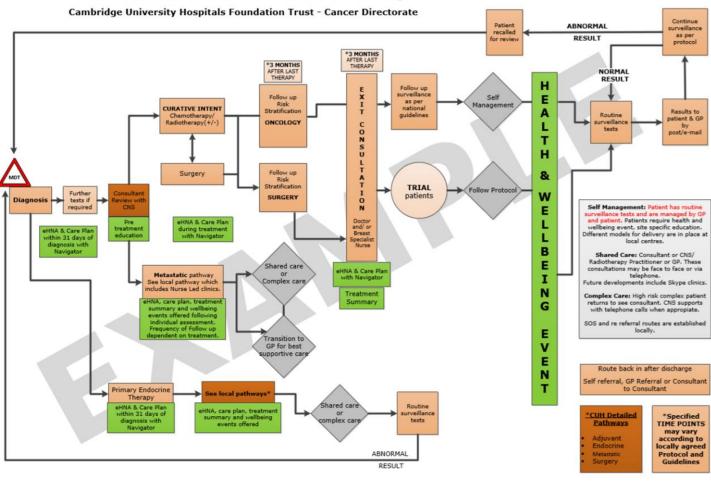
An example brief overview of these sites is detailed below. Full summaries are contained in the Annex D Case Study Report.



Breast Cancer Pathway

Figure 3-2: Risk Stratified Breast Cancer Pathway (example)

Risk Stratified Breast Cancer Pathway





The MICCP have worked on two specific areas of the Breast pathway – Adjuvant and Metastatic:

- The Adjuvant pathway had completed proposed mapping before the MICCP began in 2015. The MICCP revisited this and supported commissioning and implementation.
- During the MICCP the Metastatic pathway completed the redesign process and commissioned the new pathway revisions.

The whole Breast cancer site incorporated elements of the Recovery Package, with particular traction around use of the eHNA.



Colorectal Cancer Pathway

Figure 3-3: Risk Stratified Colorectal Cancer Pathway (example)

Risk Stratified Colorectal Cancer Pathway Cambridge University Hospitals Foundation Trust - Cancer Directorate Continue surveillance as per Patient recalled for review ABNORMAL RESULT protocol NORMAL RESULT Stratification test surveillance Self SURGERY Management Local pathways apply Results to patient & GP urveillano tests CURATIVE INTENT by post/e-mail Surgical/ Oncology HNA & Care Plan TRIAL Follow Protocol patients & Further Consultant W Self Management: Patient has routine surve Review with CNS tests and are managed by GP and patient. Patients require health and wellbeing event, site specific education. Different models for delivery are in place at local centres. tests if required Pre treatment education Standard Risk See local policies eHNA & Care Plan within 31 days of diagnosis with Navigator Shared Care: Consultant or CNS or GP. These consultations may be face to face or via telephone. Shared care ONCOLOGY Colon and Met В E Complex Care: High risk complex patient returns to see consultant. CNS supports with telephone I calls when appropriate. PALLIATIVE INTENT Treatment N SOS and re referral routes are established locally. management G Complex care Standard and high risk Anal *Specified TIME POINTS patients may be discharged to GP at years 3-5. may vary according to E Rectal & Colon patients at locally agreed Protocol and Guidelines end of oncology treatment go in to surgical follow up. Transition to GP Treatment for palliation See local Metastatic

Source: CUHFT



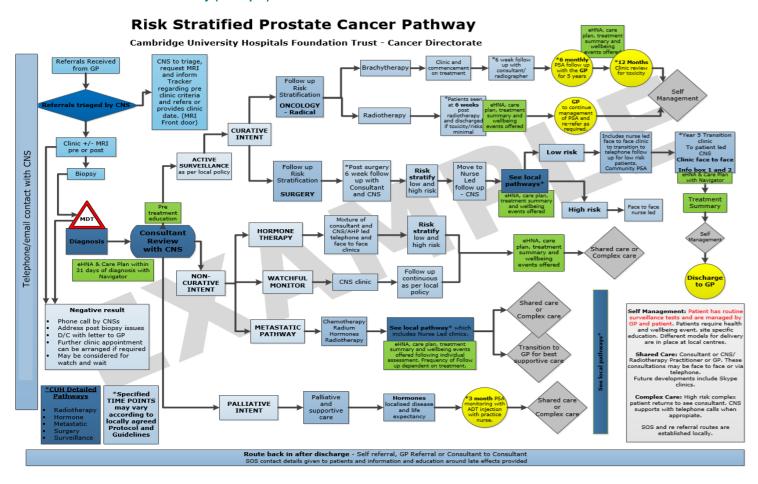
The Colorectal cancer site had four pathways engaged with the MICCP; Anal, Colon, Colorectal/Colon Metastatic and Rectal. The pathway most advanced in their MICCP journey was Anal, which completed several aspects of the redesign process and achieved implementation. This went live in December 2017 and January 2018: Anal cancer patients can now access elements of the Recovery Package including eHNAs, Care Plans and Treatment Summaries.

The other pathways were earlier in their MICCP journey, but by the time of reporting had mapped their existing pathways and risk stratified pathways.



Prostate Cancer Pathway

Figure 3-4: Risk Stratified Prostate Cancer Pathway (example)



Source: CUHFT



The Prostate cancer site had four pathways engaged with MICCP: ROBOT Surgery, Active Surveillance/Monitoring, Oncology Chemotherapy and Prostate Hormone.

- ROBOT Surgery: Of all the pathways across the sites, the ROBOT Surgery pathway was considered the most advanced in terms of its MICCP journey, with full implementation excluding Treatment Summaries
- Prostate Hormone: This pathway had a new clinic commissioned in August 2017
- Active Surveillance/Monitoring: This pathway was risk stratified and submitted for a commissioning decision for a new pathway
- Oncology Chemotherapy: Risk stratification mapping was taking place across the Oncology Chemotherapy site.



Introduction to the report

This report presents the findings from the evaluation alongside recommendations for the next steps of delivery at site and national levels. This report should be read in conjunction with other separate Annex reports:

- Annex A, B and C: MICCP Theory of Change Models, Evaluation Methodology and Economic Analysis in detail
- Annex D: Case Studies of Breast, Colorectal and Prostate cancer sites
- Guidance for others seeking to learn from the MICCP.

Key considerations

When reviewing this report, it is important to keep in mind the following limitations:

- Large programme with multiple workstreams: The MICCP is a broad ongoing programme, with multiple workstreams and activities across 23 different pathways of care. As such, the evaluation has worked to generate an understanding of what the MICCP has achieved to date and key process learning. The scale and complexity (as well as capacity pressures) led to some delays in programme implementation, limiting the available evidence base. There are data gaps, in particular regarding Treatment Summaries and clinic throughput data, as well as the clinical outcomes for PABC.
- Outcomes not yet fully realised: The evaluation ran alongside implementation of the MICCP. Many of the impacts are expected to emerge over a longer time period, as the new ways of working become embedded. As such, the findings presented indicate the outcomes emerging so far – further outcomes are expected to emerge over coming months and years.
- **Secondary data reliance**: The report is reliant in many places on secondary data; particularly in respect of PABC survey data, cancer incidence statistics, economic assessment data and monitoring data regarding Recovery Package and risk stratification implementation. Whilst care has been taken to cleanse this data and understand sample sizes, time-lags and contextual factors, it has not been possible for us to independently verify the accuracy or completeness of the data.
- Limited scope for qualitative fieldwork: The evaluation did not involve any qualitative fieldwork with volunteers involved in the programme, or with the relatives and carers of cancer patients.



4. Evaluation methodology

Overview of the evaluation approach

The evaluation was designed to generate process learning to inform implementation, as well as evidence to assess the impact and financial implications of the MICCP. It followed a theory-based approach, using mixed-methods for data collection, involving a combination of secondary data gathering, document review, two online surveys, telephone consultations with professional stakeholders, and telephone interviews with PABC, all followed by desk-based analysis.

This section reviews in more detail the key evaluation activities and approaches, as outlined in the diagram below. Further detail is contained in Annex B.

May - Nov 17 Throughout Nov 17 - May 18 Scoping and Analysis and Data collection design reporting PABC consultations Thematic, data and Inception meeting Stakeholder Data mapping and survey analysis consultations Baseline report document review Stakeholder survey Scoping interviews Interim report GP survey ToC development Final report Secondary data Key evaluation Standalone exec analysis **questions** summary Economic assessment Evaluation framework Top Tips document Transferable Pragmatic, Collaborative 'No Realistic Flexibility contextual approach production evaluation burden

Figure 4-1: Evaluation activities from May 2017 to June 2018

Source: SQW

Phase 1: Set up and scoping

Site visit and inception meeting: To clarify expectations and parameters for the study, the evaluation team leads met with the MICCP team in May 2017, for a set up meeting and Evaluation Steering Group meeting. This helped to build understanding of the background to the MICCP, implementation and progress to date, and discuss case study site sampling and recruitment.

Document and data mapping: Following the inception meeting, Macmillan and CUHFT leads provided SQW with over 140 key programme level, contextual and site-specific documents. These documents were thematically mapped and reviewed to build up a detailed understanding of the MICCP aims and objectives, progress to date and emerging impacts.

Scoping interviews: Between June and September 2017, the evaluation team conducted six semi-structured scoping telephone interviews with key stakeholders. The sample included: MICCP team members; a GP; a Clinical Commissioning Group (CCG) commissioner; Macmillan project managers; and a member of the Clinical Cancer Network.

Theory of change (ToC): Using insights generated through the document review and scoping interviews, the evaluation team designed an overarching MICCP ToC model. Once this model was approved, the evaluation team produced three further ToC models (one per case study cancer site)



which 'nest' within the MICCP model. Each ToC shows the linkages between inputs, activities, outputs and expected outcomes and impacts, with the causality, risks and underpinning assumptions explained. All four models and underpinning assumptions are contained in Annex A.

Evaluation framework and key evaluation questions: Following the ToC development, SQW worked with Macmillan and CUHFT leads to identify additional lines of enquiry for the study and to refine the originally proposed evaluation questions. This informed the evaluation framework, which was signed off by the MICCP and Macmillan leads in November 2017.

Co-production: One of the core principles of this evaluation was to work in a way which was ethical and sensitive to participants. We engaged PABC at key points throughout the study to design our approaches and tools. CUHFT advised that this was best achieved through consultation with patient representatives on the MICCP Steering Group, who signed off the PABC data collection tools in February 2018.

Phase 2: Data collection

Data collection took place in two waves: November to December 2017, and February to May 2018.

Sampling: The sampling for this evaluation was on two levels:

- 1. To identify case study sites for the evaluation; these sites were more advanced in terms of implementation, had large numbers of PABC receiving care, and are of national significance
- 2. Sampling within case study sites: case study sites varied significantly, and therefore the fieldwork plan was tailored by site (and pathway) to reflect this.

Stakeholder consultations: So that we gathered data that was both cancer pathway specific and programme wide, we segmented the stakeholder interviews to include:

- Cancer Nurse Specialist (CNS) staff (n=3): interviewing the lead Nurse at each case study site to explore MICCP implementation in detail
- MICCP team (n=3): interviewing stakeholders with different roles and responsibilities across the team to draw out wider learning
- Partners (n=5): interviewing stakeholders with specific responsibility for, or input into, an element of the MICCP e.g. eHNA, Exercise Referrals, EPIC, MCISS.

Interviews took place over the phone at a time convenient to the interviewee. Six interviews took place in November and December 2017 (to generate process learning), which informed the Interim Report. The remaining five consultations took place in February and March 2018.

Given the small number of interviewees in each cohort, interviewees have all been referred to as 'stakeholder interviewees' in this report to provide anonymity.

PABC consultations: Engagement of PABC in the evaluation took an iterative approach. Out of approximately 80-90 PABC invited to take part in an evaluation interview or focus group, five semi-structured PABC interviews took place. These generated hugely valuable learning and insight into the PABC journey through cancer care at Addenbrooke's, particularly in relation to eHNA and the Nurse-led risk stratified clinics.



Stakeholder survey: The online survey elicited details about stakeholder involvement in, experiences and perceptions of impacts emerging from the MICCP. It explored stakeholder knowledge of the programme; the extent to which stakeholders thought it made a positive difference; their confidence in information sharing; and their views on the main enablers and barriers to effectively delivering the MICCP. The survey contained 26 questions and was designed for completion by all members of the cancer workforce (except GPs). To maximise participation, the link was sent to all cancer sites, to an estimated 60 stakeholders across the cancer workforce. The survey received 27 responses.

GP survey: Given the difficulties in engaging busy GPs, we designed a separate short online survey for GPs, containing just two questions designed to explore GP knowledge and awareness of MICCP components. The Macmillan GP emailed the survey link to local GPs, and the survey was completed by 7 GPs (including the local Macmillan GP).

Secondary data analysis: We analysed relevant secondary data collected as part of MICCP, including:

- Patient satisfaction surveys: The Holistic Breast and ROBOT pathway conducted clinic evaluations using a patient satisfaction questionnaire. In total, 52 people completed the Holistic Breast survey and 35 people completed the ROBOT survey
- Workforce development feedback: Pre- and post- training feedback forms were completed by attendees of three one-day training sessions commissioned by the MICCP team
- Recovery Package data: eHNA completion data, Treatment Summary data, Care Plan data,
 MCISS referral information; Exercise Referral data.

Economic assessment: The economic assessment draws on information from the risk stratification and re-design process as recorded in Change of Methodology Recordings²² (CMRs), along with programme cost data. As the MICCP is still in delivery, the economic assessment also includes an estimate of the, as yet, un-identified (unrealised but anticipated) savings²³. The assessment includes scenarios to explore potential variations in the impact of the un-identified savings (e.g. high, medium and low) and accounts for optimism bias²⁴ in the CMR estimates²⁵.

Phase 3: Analysis and reporting

Analysis: Our 'coding framework' was based around the core topics of interest. Quantitative data was analysed in Excel; we present descriptive statistics based on the data in this report.

Baseline Report: Presented in the form of a PowerPoint slide-deck, this report explored a range of datasets and their viability in informing the evaluation.

²⁵ Data on risk stratification and attendances where the CMRs have been implemented, to help assess the robustness of estimates.



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²² The CMRs summarised the proposed risk-stratified clinics and were sent to the CUHFT internal commissioning board for agreement.

²³ Mapping outpatient data to pathways to estimate the proportion which have not been, but are expected to be, redesigned and risk stratified.

²⁴ Optimism bias can provide a correction for the uncertainty around the available evidence, through an increase in the programme costs and a decrease in the financial value of identified benefits.

Interim Report: A PowerPoint slide-deck presented to key programme stakeholders in February 2018, exploring emerging findings and informing the final stages of the evaluation.

Guidance document: A stand-alone guidance document, summarising the key learnings emerging from this study for others seeking to learn from or replicate the MICCP approach.



5. Evaluation findings – progress and implementation

This section presents key insights regarding the progress with implementing MICCP.

The evaluation findings suggest that integrating cancer care across the four MICCP workstreams was not a linear process. **Implementation of different MICCP activities varied both between and within individual cancer sites**.

Different elements of the Recovery Package had greater traction in some sites than others, and even those that became routine experienced pockets of hiatus amongst a broader trend of more consistent delivery. Staff and volunteer involvement and IT infrastructure builds happened in bursts of activity, depending on competing demands. Work to engage the wider health and social care sector, particularly GPs, was focussed on one cancer site, rather than across sites.

There is a risk of misinterpreting this picture, particularly given the difficulties of extracting data around some key MICCP activities. This **approach was a planned and pragmatic response to implementing the MICCP** in the fast paced and complex operating environment of Addenbrooke's Hospital. It was an approach which sought to maintain momentum, even when the external operating environment put delivery at risk.

This section explores some of the wider conditions affecting the MICCP, and how these key contextual factors influenced the delivery approaches.

Understanding the operating context: Addenbrooke's Hospital

Addenbrooke's is a large tertiary centre, covering 23 cancer sites, with intake from across East Anglia. With a predicted 7% increase of new cancer patients per year, the number of PABC receiving follow-up care also continues to grow, with 8,000 patients attending follow-up appointments in 2016²⁶. The **increased demand for cancer care, in a wider context of constrained fiscal conditions**, makes a powerful case for change to deliver services in a more efficient, effective way.

Daily life at Addenbrooke's had a big impact on the extent to which the MICCP could be implemented in a systematic way. The MICCP team had to adapt delivery according to the wider culture of the hospital and NHS environment, as well as competing demands. The key contextual enablers and barriers are outlined below.

Addenbrooke's operating environment

- At times of critical incidents or winter pressures, MICCP activities took secondary priority for clinicians, and non-urgent meetings were cancelled
- The wider culture in some sites has been described as 'paternalistic', meaning key staff found it hard to 'let go' of cancer care and decision making

²⁶ Taken from CUHFT Division 4 – B4: Living With and Beyond Cancer Service: to deliver risk stratified care and the Recovery Package report.



- The physical layout of individual cancer sites **varies in terms of size and space**. This has implications for delivering certain Recovery Package activities in a standardised way; for example, ensuring privacy during an eHNA consultation
- It is worth noting that **Addenbrooke's Hospital is significantly larger in size and scope** than other sites that have implemented risk stratification and the Recovery Package²⁷.

Addenbrooke's staff and volunteers

- Hospital staff turnover impacted on capacity and the workforce's skills, experience and priorities within different cancer sites
- There were reports of 'initiative fatigue' amongst staff who had been involved in a previous eHNA trial
- The MICCP trialled and tested the delivery of some activities by volunteers but there were
 variations in **numbers and roles of volunteers** across case study sites, and gaps in
 capacity when volunteers left their posts.

IT systems and information sharing

To refine (or extract new) datasets required an IT rebuild. Having recently become a
paperless hospital, the IT department was inundated with requests for new or refined
systems, and the MICCP was a lower priority compared to many other requests.

MICCP team

- The MICCP team office was re-located out of the central hospital during the early stages
 of the programme, making it more difficult to informally connect with key staff and
 volunteers and raise visibility of the programme
- The MICCP team had vacancies across all levels of seniority at various points during the
 delivery period. This meant that the team had to prioritise certain workstreams and work
 flexibly, in line with available resource and capacity
- MICCP roles tended to be staffed through fixed-term contracts, which do not always appeal to potential applicants.

In these ways, the size and scope of Addenbrooke's, and the wider environment, brought challenges (as well as opportunities) to the MICCP, and influenced both strategic planning and pragmatic decisions around implementation. Barriers remain, limiting progress in some areas.

The following sections describe how the MICCP team navigated this context to roll out strands of the programme across different sites and at different speeds, taking an opportunistic approach to implementation.



Implementation across the workstreams

Workstream 1: Patients (risk stratification and Recovery Package)

Workstream 1 consisted of two key MICCP activities: **risk stratification** of Nurse-led follow up care, and embedding the **Recovery Package**. CUHFT outlines the purpose of this MICCP workstream, in the Addenbrooke's context, below:

"By creating a 'toolkit' of interventions, namely the Recovery Package and redesigning services to enable identification of patients suitable to be managed by a shared care or self-care approach, we will create more efficient pathways and reduce unnecessary GP and outpatient appointments whilst improving care."²⁸

Risk stratification

The aim of risk stratification within the MICCP was to redesign cancer services, to identify PABC suitable to receive Nurse-led follow up care. The following diagram illustrates the vision for risk stratified follow up care in the Addenbrooke's context.

²⁸ Taken from CUHFT Division 4 – B4: Living With and Beyond Cancer Service: to deliver risk stratified care and the Recovery Package report.



Figure 5-1: Proposed Pathway of Risk Stratified Follow up Care

Proposed Pathway Risk Stratified Follow Care Stratified care (e-HNA e-HNA e-HNA End of treatment Stratified follow up Diagnosis Discharge Pre-treatment education Treatment Treatment summaries Treatment summaries **New Patient** nformation folder Nurse Led Holistic clinics Nurse led dinics and CNS contact Consultant or Nurse led CNS telephone & face Transition to follow up Telephone clinics details in clinic to face clinics/ Pre Treatment Clinic Consultant dinics appointment Consultant clinics Consultant End of Wellbeing event if not Treatment clinic attended at End of Holistic assessment Treatment Wellbeing Event Local hospital Patient led

Source: CUH: Living With and Beyond Cancer Service

The risk stratification process is also visualised in Macmillan's diagram below.



Figure 5-2: Stratified care structure



Source: NHS Improvement-Cancer, Effective follow up: Testing risk stratified pathways, May 2011



The MICCP team's **initial aim was to risk stratify all 23 pathways**. However, given the wider operating situation described above, a strategic decision was taken to prioritise early implementation of risk stratification in sites with the potential to realise **'quick wins'**. For example, to target activity at sites where:

- Risk stratification had already commenced
- A group of clinicians were interested in or already familiar with risk stratification activity and were willing to handover aspects of care to the CNS and other Nurses
- Staff had the necessary capacity and stability to embark on risk stratification activity over a sustained period of time
- Staff had the necessary knowledge and experience to deliver clinics for risk stratified patients
- Decisions around stratification were likely to be more straightforward e.g. identifiable or common points of risk in the cancer journey
- There was alignment with national strategies, including the National Cancer Survivorship Initiative: Living with and Beyond Cancer (2013) and, since the MICCP began, the Cancer Alliance Strategy, which focussed on Breast and Colorectal cancers.

By March 2018, **nine clinics had been commissioned** to enable risk stratification across the three case study sites, out of a **total of 20 pathways mapped and risk stratified** across all cancer sites. The nine case study clinics are summarised in the following table. All of these clinics are Nurse-led apart from Oncology Prostate, which is led by both Nurses and Allied Health Professionals (AHPs). Clinics are undertaken via a combination of telephone and face to face methods, depending on the timing and purpose within the pathway.



Table 5-1: Risk stratified clinics within the case study sites²⁹

Site	Pathway	Follow-up	Date clinic went live
Breast	Adjuvant	Clinic	June 15
	Metastatic	Clinic	April 18
	Metastatic	Clinic	April 18
Colorectal	Anal	Clinic	December 17
	Anal	Clinic	January 18
Prostate	ROBOT	Clinic	May 16
	ROBOT	Clinic	August 16
	Oncology Prostate	Clinic	August 17
	Low Grade Prostate/ Monitoring	Multi professional Telephone	April 18

Source: SQW aggregation of CUHFT data

Risk stratification requires relevant clinicians at the sites to come together and collaborate to make shared decisions around patient care. In some cases, this required multiple meetings, which were often challenging and time consuming to set up. As a result, **maintaining momentum was often a challenge**, particularly when a key member of staff left and their replacement brought different expertise and experience to the whole process. There were also examples where clinicians who did not understand or agree with risk stratification challenged the process of pathway mapping in their site. At these points the MICCP team had to identify a shared solution.

To help engagement with risk stratification, the MICCP team devoted significant effort to the training and development of the CNS and AHP workforce within key sites. In 2012, CUHFT submitted a Macmillan Partnership Application to develop capacity within the cancer team structure, to develop leadership roles at Band 8a level by providing backfill with Band 6 roles. This led to the appointment of lead CNS roles, and guaranteed the protected time required to develop the skills and capability to lead on service improvement and redesign. These Senior CNS team leads acted as the **integrating cancer care 'champions'** at site level; negotiating, promoting and encouraging their colleagues to engage with the MICCP and maintain its momentum.

Once a pathway was risk stratified, MICCP submitted a **Change of Methodology Recording** (CMR) to the CUHFT internal commissioning and subsequently external commissioning, outlining the proposed changes and any cost implications. The external commissioning board in some cases took **several months to decide whether to approve a clinic** or not; over this period any staff turnover or capacity crunches put clinic implementation at risk. Additionally, when a large number of **clinics (7) were commissioned simultaneously** in November 2016, this had an impact on the MICCP team's capacity to support the clinics with the next steps necessary to turn them 'live', a situation **exacerbated by winter pressures**. Risk stratification activities were of secondary priority at times of crisis.

The need to **find and sustain a group consensus** amongst clinicians at cancer sites was therefore essential at all points of the risk stratification process – from initial pathway mapping discussions, to finding suitable rooms for Nurse-led clinics and freeing up capacity for delivery. The MICCP team

²⁹ As this table shows, the Anal (Colorectal), Metastatic (Breast) and ROBOT (Prostate) pathways have two clinics commissioned.



not only provided the administrative support required to reduce the burden (and reliance) upon the cancer workforce, but also conducted extensive and ongoing work to keep staff on-board and engaged. This combined **basic administration alongside high-level influencing activities.**

Additionally, **every cancer pathway is different**, with different staff, capacity and cultures, so there was no 'one size fits all' approach on which to draw.

Considerations for the future

Across the different evaluation strands, participants described the value of risk stratified follow up care for PABC and for CUHFT, enabling the Trust to better meet the growing demand for cancer care. Participants also recognised the multiple barriers to risk stratification and the extensive work of the MICCP team to maintain momentum around the process.

Given the importance of influencing and engagement to risk stratification, one recommendation that emerged focused on a Consultant 'championing' risk stratification amongst clinicians, to keep it on their agenda.

"[It might help to overcome barriers to risk stratification] if the project team had a Consultant link. Maybe a designated Consultant or CNS who was strongly affiliated with the project. So, when there are Consultant meetings with the CNS, it is always kept on the agenda. When you have a champion, other professionals tend to buy into it more". Stakeholder interviewee

The Recovery Package

Otherwise referred to as the 'toolkit', the Recovery Package is a series of interventions which form part of an overall support and self-management package for PABC³⁰. The different interventions of the Recovery Package and how they interact with each other are illustrated in the diagram below.

³⁰ More information can be found about the Recovery Package on the Macmillan website: https://www.macmillan.org.uk/about-us/health-professionals/programmes-and-services/recovery-package



Figure 5-3: Recovery Package



Source: Macmillan

The MICCP team worked to embed the following elements of the Recovery Package:

- eHNA electronic Holistic Needs Assessment
- Care Plans
- Treatment Summaries
- Exercise Referrals
- Health and Wellbeing Events.

"[The Recovery Package] is arming patients with the tools to move forward and think about their general health now - and how to keep well in the future."

Stakeholder interviewee

"The Recovery Package is looking to provide a more holistic service to people in treatment and afterwards who are living with cancer. Physical activity, relaxation techniques, counselling, help with social problems and housing; [it is] a pathway that would help all aspects of that journey." Stakeholder interviewee

The MICCP implemented different elements of the Recovery Package to varying degrees across different cancer sites. The case study site-specific activity is outlined in Annex D. The following section explores activity at a wider programme level.

The electronic Holistic Needs Assessment (eHNA): The most widely-delivered element of the Recovery Package was the eHNA. The eHNA³¹ is a set of questions for self-completion, prompting PABC to consider and raise any concerns they might have across different aspects of their lives. In

³¹ For the MICCP, the eHNA is always completed electronically, either on the iPad in Addenbrooke's or online by a PABC at home. This is why this report refers to the eHNA (to denote the electronic mode of implementation) and not HNA (which could be completed offline/on paper).



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other words, the eHNA focusses on the whole person, and is used to inform a conversation with a care provider on issues beyond treatment or medical care. The eHNA responses are sent instantly to a Nurse, who then meets with the PABC face to face to discuss any needs or concerns identified, before signposting or referring the PABC on to relevant information or support, forming the basis of their subsequent Care Plan (discussed in further detail in the next section)³².

The MICCP received an £8,000 grant to purchase **iPads and remote WiFi for eHNA implementation,** and worked with staff and volunteers at targeted cancer sites to agree how best to deliver the eHNA. This often **depended on workforce capacity** e.g. having a CNS or volunteer able to hold the consultation at an appropriate time, and the **physical space available** in which to hold the care planning conversation. Stakeholder interviewees reported initial issues when using the technology, which delayed initial uptake of the eHNA, which were eventually resolved by the MICCP team.

As Table 5-2 below shows, there was a significant increase in the number of eHNA consultations that took place between 2015 and 2016. Stakeholders suggested that this increase was largely attributable to having dedicated and consistent **volunteer resource** at sites to hand out the iPads, and aligning eHNA completion with **staff development** objectives to motivate their engagement.

There was a slight fall in the number of eHNAs conducted in 2017, explained by a change in Macmillan administration processes to set up an eHNA; this was further compounded by capacity pressures.

Table 5-2: eHNAs completed per cancer site, 2015-2018

	Breast	Colorectal	Prostate	Other	Unknown	Total
2015 (for 2 months)	13	N/A	N/A	N/A	N/A	13
2016 (for 12, 11, 10 or 7 months*)	245	5*	63*	51*	16*	380
2017 (for 12 months)	213	3	104	60	3	383
2018 (for 3 months)	17	9	32	9	0	67
Total	488	17	199	120	19	843
Average per month 2015	6.5	N/A	N/A	N/A	N/A	6.5
Average per month 2016*	20.4	0.7	5.7	5.1	1.5	33.4
Average per month 2017	17.8	0.3	8.7	5.0	0.3	31.9
Average per month 2018	5.7	3.0	10.7	3.0	0.0	22.3

^{*} In 2016, each site started eHNAs in different months: Breast in January, Prostate and Unknowns in February, Other sites in March and Colorectal in June. The average per month (2016) has been adjusted accordingly.

Source: CUHFT's eHNA data 2018

³² For more information about the eHNA and Care Plans, see Assessment and Care Planning for Cancer Survivors: A Concise Evidence Review (2014), Macmillan and the University of the West of Scotland.



The rest of this section explores views on the timings and usability of the eHNA, from the perspective of both stakeholder and PABC interviewees.

Timing of eHNA

Macmillan recommends that the eHNA should happen at three points along the pathway. Because the MICCP risk stratified follow up pathways, the eHNA was by its nature at the end of the pathway.

"Prior to surgery, patients have numerous other forms that they need to fill in."

Stakeholder interviewee

The following table shows the different pathway stages at which PABC undertook the eHNA, broken down by case study and 'other' cancer sites.

Table 5-3: Stage of pathway at which PABC undertook eHNA, by site³³

Stage of Pathway	Breast n=488	Colorectal n=17	Prostate n=199	Other n=120	Unknown n=19
Initial cancer diagnosis	0%	0%	1%	3%	0%
Start of treatment	0%	6%	0%	0%	0%
During treatment	1%	59%	3%	18%	0%
End of treatment	71%	24%	18%	12%	0%
Follow up	3%	0%	61%	41%	0%
Other	0%	0%	1%	0%	0%
Unknown	25%	12%	17%	26%	100%

Source: CUHFT's eHNA data 2018

The key points to note from this table are:

- The largest cohort of patients who undertook eHNA within the Breast cancer site did so at the end of their treatment (71%)
- For the Colorectal cancer site, the majority undertook the eHNA during treatment (59%)
- Within the Prostate cancer site, the majority of eHNAs were undertaken during follow-up appointments (61%)
- Seven eHNAs were conducted at the initial point of cancer diagnosis/start of treatment (2 in Feb 2016, 4 in in 2017 and 1 in 2018).

Out of the five PABC interviewees, four remembered having completed the eHNA. Whilst those PABC agreed that the **eHNA** is a valuable tool to generate new conversations (explored in more detail in the PABC impact section below) there were **divergent views as to the best timing** for the

 $^{^{}m 33}$ The MICCP team record the number of PABC who are offered the eHNA but decline to complete it.



intervention. Indeed, neither PABC nor stakeholder interviewees reached a consensus on when an eHNA should take place.

On the one hand, holding an eHNA consultation as early as possible in a PABC's treatment journey presents an opportunity to identify and address key concerns and think ahead to potential forthcoming issues at the beginning of the process.

"This programme is good at pre-empting [worrying] symptoms so patients are aware of this at the start and not [just at] the end." Stakeholder interviewee

Having an early eHNA was preferred by some PABC interviewees, particularly those who would have liked the access to relevant information at an early point in their treatment, describing this as a gap in their care experience.

"I can't think when I did my eHNA. But when it was presented to me I thought maybe it could have been a few months earlier. Some of the questions seemed related to earlier experiences in the cancer programme." PABC interviewee

"It would have been very helpful to have had the eHNA earlier on... [because] there really wasn't any consideration of the psychological impact of the treatment for me early on, and doing this questionnaire would have brought it out as an issue, and it would have been much better to have on the table earlier."

PABC interviewee

By contrast, PABC who described feeling shocked or numb when receiving their cancer diagnosis felt that an eHNA at the beginning of the cancer journey would be too early, and not give PABC enough time to digest information or identify their concerns.

"I didn't always ask the right question as my brain had gone dead at the time...

Maybe part of the difficulty is that you're probably given the opportunity at the time to talk, but sometimes it's something that comes to you several weeks after, how you're feeling now, whether you have treatment, when you're back at home. It would be good to have an opportunity to talk to a Nurse, when you've had chance to regroup. Like when it's the 3 months recall with the Doctor or Nurse [or] when you get signed off. That seems the right sort of timescale." PABC interviewee

Despite divergent preferences regarding timing, there was agreement that **the eHNA conversation could be helpful at least at the end of treatment**, particularly at the point when PABC experience fewer follow up appointments at the hospital. As one PABC described it, this could be a 'scary' point for PABC who were otherwise used to ongoing hospital monitoring. For this interviewee, a closing eHNA would be one way to prepare for life in survivorship.



"When you finish your cycle [of treatment] it's quite scary for people. [It can] feel like you're under the wing of the team and they're on top of everything. And then you don't need to see them for a month and you feel – oomph." PABC interviewee

Supporting PABC who might be 'a bit lost' at the point of discharge was identified as another benefit of an end of treatment eHNA.

"[It] is an opportunity to meet with a patient who's literally just finished treatment who may be a little bit lost shall we say; they've had a lot of to-ing and fro-ing to the hospital and a lot of intense treatment, they've seen a health professional on a regular basis linked to the end of their treatment. What this allows us is to sit down as a face-to-face consultation with the patient, to gain from them what they understand has just happened." Stakeholder interviewee

Recognising that all PABC digest information differently and have different needs and preferences, PABC interviewees suggested that **the eHNA could be offered to PABC at several points throughout their cancer journey.** This is not to make it a mandatory or a tick-box exercise (which would be counter-productive), but so that PABC are aware they can have non-clinical, holistic conversations when they are ready and willing to.

Usability of the eHNA

Alongside the debate regarding the 'ideal' time (or times) to hold an eHNA were comments around the eHNA process. Of the four PABC that remembered completing the eHNA, three completed it in the hospital, followed by with an immediate conversation with the lead Nurse. One completed it online at home and then attended Addenbrooke's for an appointment to discuss the results.

For the PABC interviewees who completed the eHNA in hospital, they were approached on the day of their appointment, introduced to the eHNA and asked to fill it out in the waiting room or corridor. Interviewees felt that the **eHNA app was intuitive and the iPAD easy to use**. Interviewees also felt that the **process was streamlined** by meeting with the Nurse to discuss the findings the same day, whilst fresh in their minds. One note of caution around the technology came from stakeholder interviewees with experience of the eHNA, who questioned how suitable the electronic application was for some (and particularly elderly) PABC. These interviewees reported **mixed confidence**, **trust and capability in using the technology**.

One PABC interviewee questioned whether waiting for him to complete the eHNA was a good use of the Nurse's time. This PABC would have preferred to fill the eHNA out in advance, preferably online at home before the appointment date.

"I went as normal, I was in the waiting room just waiting to get the blood test results, and as I was walking down the corridor with [the Nurse] she handed me the iPad and asked if I could key in any problems I would like to discuss. There were 10 [questions] around certain problems you might have [and] it took about 10 minutes [to complete] I suppose. But whilst I was doing that I was in the corridor and she was waiting for me to complete it. She knew on her PC when I'd completed it. And she called me in to discuss each of the topics that came up.



[But] I felt that that 10 minutes wasn't probably a good use of time for her, waiting for me to key in the various problems. It might have been better to have given it to me in the waiting room... Or better, online, to fill something in online, to get [the results] to the Nurse before the assessment." PABC interviewee

The PABC that completed the eHNA online at home reported that this was a convenient and straightforward process, and meant that the eHNA conversation was clearly separated from routine follow-up appointments³⁴.

"Filling out the assessment was fairly easy and it didn't take that long to complete. I did it online at home and [the Nurse] set up an appointment with me to discuss face to face. It was a separate appointment, rather than grabbing me during of my other appointments." PABC interviewee

Other PABC interviewees who reported that they would prefer to complete the eHNA online at home suggested it **could usefully be introduced by a short online video**. This would help to explain the purpose of it (and so distinguish the eHNA from other forms PABC have to complete before hospital appointments) and encourage participation.

Scope of the eHNA

PABC and stakeholder interviewees reflected that the eHNA seeks to capture a lot of information within an hour-long consultation, particularly when multiple issues are identified to discuss in detail.

"I thought it was very comprehensive. In the back of my mind was the worry that someone who has got a complex situation could end up with so many issues flagged up that it would be hard or time consuming to deal with in one conversation." PABC interviewee

Despite this concern, PABC interviewees who did identify a larger number of issues felt that they were adequately covered in the subsequent conversations.

Patient Navigators

The MICCP team began recruiting for three Patient Navigator roles in 2018. There was consensus amongst stakeholder interviewees about the potential of using Patient Navigators to oversee the eHNA process in a consistent way and take some of the work away from the clinical and volunteer workforce at sites. As one interviewee commented:

"From my understanding, Patient Navigators will almost have their own clinics and be site specific... It's good they're going to get the Navigators as that will

³⁴ Analysis of CUHFT eHNA data conducted in 2018 suggested that only 2% of eHNAs were conducted online at home, which equates to 18 assessments overall.



take the strain off the [clinical] teams. The fact they've been able to get the Navigators on board will be a big positive." Stakeholder interviewee

The learning from the case study sites is that volunteers proved instrumental in providing the additional capacity and resource needed to implement and maintain traction around the eHNA. This reliance carried inherent risk, not least as evidenced when volunteers left posts and implementation subsequently dropped off. The Patient Navigators are expected to provide a level of consistent and dedicated support with a lower level of turnover risk and a fixed number of working hours each week. They will not necessarily replace volunteers in case study sites but they will bolster capacity with a guaranteed resource level.

Considerations for the future

There was a tension between delivering a standardised approach and flexing the implementation of the eHNA at site level. For example, stakeholder interviewees tended to understand the need for a degree of consistency of approach, but were also keen to adapt it to their site-specific context. Examples of variation to consider might include verbally talking through the eHNA with PABC or providing a paper copy for completion.

Additionally, the lack of consensus as to the best timing for an eHNA might further support an element of local flexibility, to encourage sites to trial the eHNA (and other Recovery Package elements) in ways that work for them and their patients, but within parameters of 'good practice' guidelines agreed with Macmillan.

Feedback from PABC indicates that they would consider completing the eHNA at home before an appointment at hospital (providing they were fully briefed on the eHNA and the importance of completing it, and that the format was user-friendly). This would help to minimise the space and time required for the eHNA completion process within Addenbrooke's.

Finally, the new Patient Navigator role provides an opportunity to widen uptake of eHNAs and to monitor implementation and PABC experience, within both existing and new sites.

Care Plans

A Care Plan is intended to follow the eHNA conversation between the clinician and PABC. It is designed to explore the needs and concerns identified by the PABC via the eHNA, alongside the specific goals, actions and approaches to address them. Macmillan suggest that Care Plans act as a tangible record of discussion that the PABC can refer to throughout their treatment and beyond.

"The Care Plan will be developed in partnership with the patient, and become a part of the patient held record that can be reviewed to ensure that actions have been taken and revisited if health and social needs change." (Assessment and Care Planning for Cancer Survivors: A Concise Evidence Review, 2014)

The following table outlines Care Plan activity across the three case study sites and other cancer sites.



Table 5-4: Care Plans completed per site, 2015-2017

	Breast	Colorectal	Prostate	Other	Total
2045 (for 2 months)					
2015 (for 2 months)	13	N/A	N/A	N/A	13
2016 (for 12, 11, 10 or 7 months*)	245	5*	63*	51*	364
2017 (for 11 months)	179	2	73	35	289
Total	437	7	136	86	666
Average per month 2015	6.5	N/A	N/A	N/A	6.5
Average per month 2016*	20.4	0.7	5.7	5.1	30.3
Average per month 2017	16.3	0.2	6.6	3.2	26.3

^{*} In 2016, each site started Care Plans in different months, Breast in January, Prostate in February, Other sites in March and Colorectal in June. The average per month (2016) has been adjusted accordingly

Source: SQW aggregated CUHFT's data (2017)

There were **666 Care Plans** generated between November 2015 and November 2017. The largest proportion of these occurred at the Breast site, which produced a total of 437 Care Plans over the period. The dip in Care Plans at the Breast site between 2016 and 2017 can be largely explained by staff turnover.

Stakeholders with experience of Care Plans agreed that they were useful for PABC, particularly in summarising the telephone numbers to contact in case of queries and/or concerns, and what symptoms to look for. As such, they were **welcomed as a highly beneficial tool** in supporting PABC to self-manage and have control over their care.

Interviewees pointed out a number of ways in which the **usability of Care Plans could be improved.** For example, there is no **spell check function**, which meant that Care Plans often included spelling mistakes. Additionally, Nurses sometimes **ran out of time** to complete the template, meaning they had to do it after the appointment, taking up more of their time. Nurses who were slower at typing found the Care Plan particularly time consuming. Concerns over lack of time meant that Nurses might **prioritise certain PABC concerns** during appointments, focusing on their top three issues for example, as a means to focus the conversation and ensure they had the time to complete the Care Plan.

Despite four out of the five MICCP interviewees remembering having an eHNA, **none specifically recalled receiving a Care Plan.** There was no way of establishing whether these interviewees had received a Care Plan. However, this may suggest that PABC receive a wealth of information, from a wide range of partners and on a variety of areas, making it difficult for them to attribute information to specific sources³⁵.

³⁵ Three PABC interviewees had access to a folder of information they had gathered during their cancer care. This included information about treatment and appointments, as well as leaflets from partners, but did not seem to include a Care Plan.



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Considerations for the future

Like eHNA, Care Plans feature in the Cancer Alliance Strategy. The MICCP team have plans in place to support further roll-out of Care Plans in future, particularly in terms of explaining IT requirements to CNS staff across sites (via the newsletter).

Gathering more specific feedback from Nurses on the Care Plan template could be a useful exercise, to understand whether there are any other ways in which the completion process could be sped up, for example by introducing spellchecking functionality.

The Patient Navigators are anticipated to work with PABC to support them through the eHNA process, address any non-clinical concerns and then escalate clinical concerns to the CNS to address within the Care Plan. As with the eHNA, it will be important to monitor completion rates and PABC experience of the process (and capture staff reflections), to ensure it works as effectively as possible moving forward.

Treatment Summaries

Treatment Summaries form a core component of the Recovery Package toolkit, **designed to improve the flow of information and improve communication** between PABC, secondary care and GPs. Treatment Summaries were also intended to support Workstream 4 of the MICCP, to help engage the wider system, most notably GPs.

Workstream 4 is described in more depth below, explaining how the overall workstream was delayed to prioritise other elements of the programme. As such, Treatment Summary activity was mainly trialled in one case study site – Colorectal – strategically selected to capitalise on senior stakeholder engagement. The activity involved designing and testing a tailored Treatment Summary template for that site.

The Colorectal site developed a Treatment Summary specifically for Lower Gastrointestinal (LGI) cancers. This was designed in consultation with the Macmillan GP and was approved and built into EPIC to facilitate trial implementation. Stakeholders with experience of Treatment Summaries agreed that the **template was user friendly**, particularly the use of drop-down boxes which correlate with the LGI section of the EPIC site, reducing the need for free text content. The next stage is for the template to be built into EPIC and linked to the relevant PABC data.

Whilst stakeholder interviewees had different experiences of Treatment Summaries, they agreed they were useful for PABC in pulling together helpful contact information and relevant symptoms to watch out for, to support self-management during recovery. Stakeholders with less experience of Treatment Summaries asked for more information and requested training on them before wider roll-out. No PABC interviewee remembered receiving a Treatment Summary but, as with the Care Plan, it was not possible to establish whether they had actually received one or not.



Considerations for the future

As with Care Plans, support to speed up the process of completing Treatment Summaries was called for by interviewees: some Nurses type more slowly than others and found it time consuming to complete the notes. Support might include site-specific IT 'builds' using learning from the Colorectal Treatment Summary template.

Interviewees suggested that more work could be done to support Nurses, GPs and PABC to fully understand how a Treatment Summary is different to a letter or discharge summary. They called for a briefing or training on how to complete a Treatment Summary once rolled out more widely.

Exercise Referrals

The Rehabilitation and Exercise during Addenbrooke's Cancer Treatment (REACT) scheme was introduced as a **new scheme** run by a CUHFT Senior Physiotherapist, catering for people used to exercise but unsure about starting again during or after cancer treatment, plus PABC who have never exercised and are unsure of where to start. The scheme **taught specific exercises and how to exercise safely, encouraging sustained exercise**.

Alongside the REACT scheme was the Cambridgeshire County Council (CCC) Active Communities Lifestyle team (ACL). This team was approached directly by the MICCP team to discuss the potential of setting up an Exercise Referral scheme for patients at the end of their treatment. The ACL trained up four instructors in Cambridgeshire to specifically work with PABC as advised by Addenbrooke's health professionals, and worked with the MICCP team to create a referral system.

Setting up the Exercise Referral schemes involved multiple stakeholder conversations and IT development work through the EPIC IT team, to facilitate information sharing across partners. The whole process took time to work through, requiring agreement from a wide range of stakeholders, and it was set up just as Addenbrooke's switched to a paperless system (which meant that the EPIC team were fully committed with working on the wider EPIC launch).

"It took a long time. It takes an awful long time [for] processes to change. And if you imagine all of the things going on at Addenbrooke's, [there's] a lot of busy people in there. It's one little crumb of what needs to be done." Stakeholder interviewee

Nonetheless, despite these challenges the referrals to both exercise schemes, and the partnership built up with CCC, were seen as key successes of the MICCP, offering opportunities to sustain and build on in the future. The MICCP team has created a streamlined process for the cancer workforce to refer PABC through to both the ACL and REACT teams.

The following chart shows the number of Exercise Referrals to CCC generated through MICCP³⁶.

³⁶ This chart does not reflect the total number of Exercise Referrals to the REACT team or to the Cambridgeshire County Council exercise scheme as that data is currently not available.



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Table5-5: Total numbers of Exercise Referrals generated by each case study site, other sites and overall across MICCP, 2016-2018, showing totals and monthly averages

	2016 (7 months)	2017 (12 months)	2018 (3 months)	2016 monthly average	2017 monthly average	2018 monthly average
Breast	3	14	4	0.4	1.2	1.0
Colorectal	4	1	0	0.6	0.1	0.0
Prostate*	6	39	7	0.9	3.3	1.8
Other**	5	0	0	0.7	0.0	0.0
Total	18	54	11	2.6	4.5	2.8

^{*}Prostate includes 1 referral in April 2018

Source: MCISS data (2018)

Considerations for the future

Now that effective referral and delivery structures are in place, stakeholder interviewees called for the MICCP to **widen the scope of the Exercise Referral system** to engage a greater number of sites. This would require awareness-raising amongst a larger number of clinicians, to increase the number of individuals referring in to the scheme. This must however be aligned with capacity in the Exercise Referral schemes, to ensure demand does not exceed supply and create pressures in the system.

"We do a lot of exercise referrals and the process is really good. It works well but we only really get referrals from [a small number of] clinicians and considering the number of teams we have that's not much... We've done work with our volunteers to highlight the evidence around how positive exercise is as part of survival – maybe we could do that with clinicians." Stakeholder interviewee

Health and Wellbeing (HWB) events

The MICCP team originally planned to hold six HWB events per year but changed their focus as implementation of the programme got underway. Throughout the MICCP to date, two HWB events took place, one in 2015 and one in 2016.

Interviewees with knowledge and experience of the HWB events described them as useful in bringing together a wide range of practitioners, offering different kinds of knowledge and support to PABC. These partners were both from within and external to CUHFT, including charities including Maggie's, Age UK and the Carers Trust UK, as well as a range of independent professionals such as providers of complementary therapies, mindfulness and yoga. CUHFT supported with Physiotherapist, Occupational Therapist, Radiotherapist and Dietician input.



^{**}Other includes 1 blank

The learning from the event evaluations was that they had been successful but resource intensive. Additionally, the multiple partners had different priorities for the event which didn't necessarily align. The learning from these events fed into the business case for sustaining the programme.

Considerations for the future

Learning from the HWB events indicates that these are resource intensive to deliver and require extensive management by a large steering group in order to align different partner priorities, meaning that they are difficult to resource at Trust level.

There may be economies of scale through a regional approach, which Macmillan could usefully play a key role in.

Workstream 2: Workforce and culture change

The second MICCP workstream **focused on workforce development, with the longer-term objective of achieving culture change**. The MICCP designed a **Learning and Development (L&D) programme** to be delivered to the workforce within the Cancer Directorate. The aim was to run the programme for two years starting in autumn 2016. The rationale for the training, and how this was intended to support wider culture change, was outlined in the CUHFT Cancer Directorate Core L&D Programme Draft:

"To meet the needs of patients within the Cancer Directorate at CUHFT, we need to change the way in which we deliver care; moving away from a predominantly medical model to a more holistic approach that empowers and enables patients, promoting wellbeing, independence and supported self-management. Healthcare professionals need to be equipped to deliver risk stratified care and the Recovery Package, using different approaches to communication and possessing a knowledge of survivorship". (CUHFT Cancer Directorate Core L&D programme Draft, 2016)

The core programme consisted of the following courses:

- Supported self-management education and training programme
- Advanced communication skills
- Sage and Thyme.

The content of the training was evidence based and focussed on empowering the individual. It aligned with a wider drive towards **person-centred approaches within the NHS Five Year Forward View and CUHFT's Learning & Development Strategy**.

The training was advertised to all staff groups (qualified and non-qualified, including medics) across all cancer sites in CUHFT. The majority of people attending were from nursing and AHP teams; no medics attended. Three one-day training courses were held for staff in May, June and October 2017, and a total of 21 staff members attended one of these courses.



Attendees filled in questionnaires pre- and post-training, which focussed on their practice and attitudes. The findings show that the **training had an immediate impact on the workforce's knowledge and values**, particularly in terms of their perceived role in relation to PABC. This is explored in greater detail in the 'impact on the workforce' section.

The stakeholder survey asked respondents to indicate the extent to which they agreed with the below statements around future training:

- I believe additional training/development courses would improve my confidence in supporting PABC
- I believe additional training/development courses would improve my ability to effectively support PABC.

All 10 hospital support staff and volunteers completing the survey either agreed or strongly agreed with these statements, adding a range of positive comments on the importance of training to continued professional development and the potential for this to improve care for PABC.

"Any training for staff to improve their communication skills, resilience, knowledge of cancer patients' experiences etc. is beneficial to improving patient care." Hospital support staff

"I think it is important to have regular training to be reminded of areas that do not come up often during discussions with patients. Also, as your own experience with patients increases, the training has a different impact on you and you take other things away from it each time." Hospital volunteer

For the eight medical and clinical professionals that responded to this question, six strongly agreed. Like hospital support staff and volunteers, they described the benefit of life-long learning to help improve confidence and skills.

"I think no matter how long you have been qualified you always need to update your skills, particularly communication. It's so important to take time out from the day to day firefighting to actually think about what you do and how you could do it better."

"[It is] always good to have more training, you never stop learning."

"Ongoing support and training to practice/update and learn new skills in a safe environment always helps improve confidence and effectiveness."

One note of caution was raised over the ability to embed learning from one-off short courses in practice, and suggested that a schedule of ongoing training may be more effective in sustaining impacts.



"Life-long learning should be central to anyone caring for people affected by cancer [but] a one-day course does not make us experts. The risk of one-off courses is that they become tick-box [exercises] and we assume skill is achieved by attendance, but it should also be assessed and supported in the workplace."

Medical or clinical professional

Nonetheless, the findings suggest there is appetite for further training to ensure ongoing learning at different levels within the core cancer workforce.

Considerations for the future

Team-based training

Feedback from stakeholder interviewees suggests that training is most effective when targeted at whole teams, i.e. the team that is working together trains together, rather than bringing together staff who wouldn't normally work together for training. They felt that team-based training:

- Could be more targeted to the needs and context of the cancer site
- Had a higher chance of changing site culture and behaviour, as staff could work together to implement what they have learnt.

However, releasing teams (or even partial teams) to attend training is likely to be difficult in the context of increasing workloads and clinical demands. Encouraging whole team attendance where possible, even if not all at the same training session, may help with this.

Volunteer training

Volunteers played an important role in delivering the MICCP in a number of ways, and were crucial not only to the quality of the PABC experience but also in providing additional resource and capacity to support busy clinicians. Whilst the future CUHFT integrated cancer care model includes Patient Navigators to oversee activities delivered by volunteers, continuing to support volunteers with training (particularly given how well it was received), may offer benefits. Specifically, it is likely to help improve the quality of care and keep volunteers motivated and engaged over the longer term. Ensuring a quality training offer may also support volunteer recruitment.

Workstream 3: IT systems

Workstream 3 focused on a range of changes to the IT infrastructure, to facilitate the flow of information across cancer services. This included several Recovery Package elements which depended on an alteration to the existing EPIC system to support them:

- Treatment Summaries: information about the PABC journey, for example specifics relating to treatment or medication, to be shared between secondary and primary care
- Care Plans: information drawn up in response to the eHNA, to be shared between secondary care professionals and PABC
- Exercise Referrals: the system that facilitated PABC referrals to the REACT or ACL exercise schemes



- eHNA: use of iPads to complete the eHNA electronically
- eHNA: loading eHNA onto MyChart, so that PABC could complete and submit the questionnaire from home.

Whilst the EPIC team did support a number of builds for the MICCP, securing EPIC team time emerged as one of the consistent and most insurmountable barriers to MICCP delivery. Changes to IT systems took a significant amount of time to approve, and then there was a secondary lag before these were implemented or built. There remain several outstanding requests logged but not yet approved, for example the functionality to extract data on the use of Treatment Summaries. This situation led to **staff frustrations**, recognising the dependency on the IT infrastructure to the delivery of their work and the wider MICCP.

"[Our request was] not on the priority list... Since we started over three years ago, it's been coming and is on the cards, but it's really taking an awfully long time." Stakeholder interviewee

There were multiple reasons for the delays to EPIC builds. Work to tailor EPIC was an ongoing exercise. The bi-annual EPIC upgrade meant that the new functionality and technology was constantly being adapted to the needs of the Trust. Given this situation - and given the IT team's capacity - having an EPIC request reach the top of the IT team's priority list was difficult to achieve.

Systemic delays to implementing EPIC IT builds had a significant knock-on impact on the MICCP team's ability to progress certain aspects of the Recovery Package, such as uploading Treatment Summary templates across other cancer sites and being able to extract the data required to monitor and analyse implementation. Furthermore, the MICCP team found it difficult to push requests further up the IT development priority list, given the large volume of equally important requests in the system.



Considerations for the future

Given the importance of EPIC builds to future MICCP delivery, a review meeting with the EPIC team may present an opportunity to review and prioritise requests in the pipeline, by clarifying the different requests and understanding the interdependencies. This may also help to generate an agreed workplan or timeline, to help manage stakeholder expectations on all sides and prioritise aspects of MICCP for the IT team.

Workstream 4: Partner engagement

Workstream 4 was set up in recognition that **whole-system change cannot happen within secondary care alone**. As such, the MICCP included a workstream to engage wider partners across the cancer workforce, including GPs, the voluntary and community sector, CCC and other strategic stakeholders including the Cancer Alliance and CCG. There are various ways in which the partners worked alongside the MICCP team to support implementation:

- CCC's ACL team trained up four instructors specifically to work with PABC across Cambridgeshire and co-produced an effective Exercise Referral process
- Charities, independent providers and CCC participated in the HWB events, providing practical demonstrations such as yoga, exercise and juicing, and handing out information on specific forms of support available to PABC
- The Macmillan GP's involvement in the Treatment Summary template trial at the Colorectal cancer site, supporting the design of the new template before it was built into EPIC
- MICCP team member networking with the Cancer Alliance, by attending strategic meetings out of Addenbrooke's to raise awareness of the work underway
- MICCP team members attending CUHFT senior leadership team meetings to raise awareness of the MICCP and identify ways to unblock barriers to implementation.

In addition, the CUHFT MICCP team worked closely with different Macmillan staff over the course of the programme, particularly to learn from risk stratification and Recovery Package activity at other Trusts.

Workstream 4 was primarily intended to drive wider GP engagement, particularly through the rollout of Treatment Summaries. However, IT issues and delays, staff turnover and competing MICCP priorities meant that the team decided to be realistic about this wider workstream and focus on other aspects of the MICCP, e.g. eHNA implementation.



Considerations for the future

There is a risk associated with delaying this workstream, from both a GP and MICCP team perspective, particularly around communication and clarity about the aims and activities. This report may present an opportunity to engage key GPs to review the MICCP progress so far and discuss what is possible through the Treatment Summaries, not to mention other methods to improve the flow of communication between care providers in future.

The Macmillan GP, engaged with the MICCP through the Treatment Summary trial, could act as a 'champion' to encourage the buy-in and wider engagement of GPs. Additionally, CCG events for GPs may present an opportunity to raise awareness of the MICCP and secure their buy in with a clear 'ask' and offer. The 'offer' must minimise the burden of engagement and present clear benefits for GPs and their patients.



6. Evaluation findings – outcomes emerging

This section reviews the impact of the MICCP upon PABC, the cancer workforce, cancer services and the wider cancer system.

Outcomes for people affected by cancer

One of the primary objectives of the MICCP was to improve the experience of PABC. By implementing aspects of the Recovery Package and introducing risk stratified follow-up clinics, the MICCP sought to increase the number of opportunities for PABC to express their needs, improve the quality of those conversations, tailor information and improve the overall experience of care.

This sub-section explores the extent to which (and the different ways that) stakeholders and PABC believe the MICCP has opened up new conversations, improved experiences and embedded new processes to help PABC self-manage in the longer term, as they move beyond cancer treatment and into survivorship.

PABC opportunities to express their needs

The stakeholder survey asked respondents to consider the extent to which they agreed that the Recovery Package toolkit supports PABC to express their needs. **Exercise Referrals were viewed particularly positively**, with 17 respondents either agreeing or strongly agreeing that they supported PABC.

Table 6-1: The extent to which respondents agree the Recovery Package elements support PABC to express their needs

	Strongly Agree	Agree	Don't Know	Disagree	Strongly Disagree		Unknown	Total
eHNA	10	4	7	1	1	2	2	27
Care Plans	9	5	9	0	0	2	2	27
Treatment Summaries	7	6	9	1	0	2	2	27
Exercise Referrals	9	8	6	0	0	2	2	27
Health & Wellbeing Events	8	7	8	0	0	2	2	27

Source: SQW Analysis of Stakeholder Survey

Widening the conversation through the eHNA

The purpose of the eHNA is to shift the conversation away from focusing exclusively on treatment and medicine, to a wider more holistic reflection of PABC wellbeing and needs.

Of the five PABC interviewees, four remembered having an eHNA conversation. For the PABC who didn't specifically remember the eHNA, the memory of cancer diagnosis was characterised by a sense of shock, feeling numb, making it difficult to remember specific conversations or attribute information to a particular source. This is significant as it illustrates **differences in how PABC are able to digest information**, not to mention identify and articulate concerns, at a time of crisis.



"I don't remember the eHNA I'm afraid. The whole process was such a shock.... I had been asked in appointments and clinics if I'd got any questions. But I was rather numb to it." PABC interviewee

Interviewees that did remember the eHNA described how the thematic topics – from spiritual, financial, to mental health and fitness – **prompted them to think about and recall different concerns** that they might not have otherwise felt relevant to mention. Even those PABC who considered themselves particularly capable of finding their own information and were well-supported by family and friends described ways in which **the eHNA gave the opportunity to think more widely or access relevant information.**

"On the whole I didn't feel I was necessarily as in need of it as other people might be. I'm quite independent and strong willed [and so] I was getting on with sorting things out for myself. But there were a couple of things [that came out of it, including] my fitness. I haven't worked on that since my initial diagnosis. And as my fitness level has dropped my core strength has gone. And I needed some advice for my diet for my stoma, I wanted to expand my diet, thinking that it would give me more nutrition." PABC interviewee

Two PABC completed the eHNA after several years of treatment and follow up care. For these patients, the eHNA represented a marked contrast to previous conversations with hospital clinicians which had focussed on physical health. Both described how the eHNA 'opened up different conversations'. For one interviewee in particular, the eHNA was his first opportunity to speak to a professional involved in his cancer care about his mental health.

"[After five years of treatment at Addenbrooke's] I was surprised by how wideranging the eHNA was. From my perspective it was a really good thing. It was able to capture a lot more than through the normal visits, which had involved the Nurses going through their own checklist of questions which were focussed closely on the Prostate cancer and ongoing side effects. Whereas this time it highlighted some issues I wouldn't have mentioned before and Nurse wouldn't have asked me about... It brought in a discussion about my depression which neither of us would have thought about before. And we talked about some of the psychological effects of the treatment which have not been talked about before. And in talking about that, some of the things I assumed I had to come to terms with, it turns out there were other options for. It was definitely worthwhile in that respect." PABC interviewee

Self-management through tailored information

The stakeholder survey asked respondents to consider the extent to which they agreed the Recovery Package toolkit supports PABC to self-manage by giving them relevant information. As Table 6-2 outlines below, stakeholders tend to agree that the Recovery Package supports PABC to access information that helps them manage their condition. The results suggest that there remains a challenge to reduce the number of times PABC have to tell their stories to different providers.



Table 6-2: The extent to which survey respondents agree the Recovery Package elements support PABC to self-manage by giving them the relevant information

	Always	Some- times		Occasi onally	Never	N/A	Un- known	Total
PABC are able to access information about services that help them manage their condition	5	18	1	1	0	1	1	27
PABC are aware of who to contact for support	6	16	0	3	0	1	1	27
PABC are confident that their information is effectively shared among providers (and so do not need to repeat their story multiple times)	2	8	6	8	1	1	1	27

Source: SQW Analysis of Stakeholder Survey

The rest of this section explores the different ways that the MICCP has generated tailored information that supports PABC to self-manage during treatment, follow-up care and beyond.

Self-managing through the eHNA

PABC interviewees described the nature of the needs raised through their eHNA and the information they received in response. The **nature of concerns spanned a wider range of issues**. PABC who were concerned about their fitness were referred to the REACT Programme or were given advice and reassurance about walking to keep fit. Concerns about diet and nutrition received a referral to the Addenbrooke's in-house dietician. One PABC who was having problems sleeping had been debating whether to discuss the situation with his GP; the eHNA conversation prompted him to make an appointment and he now has medication to help.

"One thing I had was sleep problems, choking as I go to sleep. [The person reviewing the eHNA] said that if you're still concerned to contact your GP. And I said I had an appointment coming up and I did go to the GP... It did trigger it in that sense. I thought it was worthwhile." PABC interviewee

As an invitation to discuss longer-standing concerns, the eHNA prompted PABC to open up about personal issues affecting their peace of mind or mental health. One PABC with two daughters had been worrying whether her Breast cancer diagnosis was hereditary. At the end of treatment, she was offered an eHNA and described how she was initially conflicted about completing it as she was so eager to move on, away from thinking about cancer. However, during the conversation she talked about her concerns of having genetic Breast cancer and was subsequently referred for testing.

"[After I finished treatment] I kind of wanted to get on with life and forget about [cancer]. With a new grandson and my daughter married, what I wanted to do was get back into my [happy] bossy mode! But I was worried about my girls. My biggest worry was that this could have been genetic. I did have an aunt on my father's side who had Breast cancer. So [after the eHNA] I went on another scheme they were doing to find out whether the cancer was genetic. And mine isn't, which relieved me very much... The fact they'd bothered to find something to put my mind at rest [was brilliant]." PABC interviewee



Self-managing through exercise

Exercise was raised repeatedly as one significant area where PABC were able to feel in control of their own recovery and keep themselves healthier over the longer term. PABC referred to exercise schemes fed back to instructors that **exercise helped them 'get back to normal'** and PABC interviewees described how Exercise Referrals helped them build their strength and commit to ongoing exercise.

"Cancer treatment is full of things being done to you, and I think patients lose their autonomy and control over things, whereas exercise and rehab is something that's got potential to have a huge impact on their long-term prognosis but is something they can do themselves – something they have power over. They might not have any control over whether their drugs are working, or if radiotherapy has done the job, and patients are scared, they've had life changing treatment and surgery and their bodies feel different, they don't know what to do anymore." Stakeholder interviewee

The many benefits of exercise described by PABC testimonies regarding the REACT programme include the **ability to make informed healthy choices in future**, as well as the chance for **camaraderie with others in group sessions**. PABC interviewees suggested that the Exercise Referral system worked well and that their **sessions were tailored** to their individual needs.

"With regards to the exercise, [the Nurse] referred me to REACT which is a programme running within the hospital. There are 10 people, we go to the gym on a weekly basis. We do an exercise programme, running etc. to build up strength. It's very useful, the exercise is tailored to what I can achieve around my stoma." PABC interviewee

Furthermore, exercise was reported to be sustained by PABC interviewees who had been referred to REACT. One PABC reported how the referral helped them feel fitter and regain their strength, and another noted how it acted as an incentive to do more exercise in the longer term.

"I learnt that I wasn't that strong in the legs. And it reinforced to me to keep moving and keep agile... My husband noted the other day that I can get up and down with the grandson but not to make a cup of tea!" PABC interviewee

"It was certainly helpful to be referred to the REACT, as I'm finding it's given me a bit more incentive to do exercise." PABC interviewee

Some PABC are not only continuing with exercise but also encouraging their family members to get fitter too.



Improved PABC experience

By supporting PABC to express their needs and providing information to support their self-management in future, the **MICCP sought to improve the overall PABC experience**, both during their time receiving care at Addenbrooke's and through survivorship and beyond.

Given the evaluation timescales, the study focussed on improved patient experience in the shorter term, specifically exploring the overall impacts of Recovery Package elements and experiences of the risk stratified clinics upon PABC. These areas are explored in more detail below.

'Validated as a person'

PABC interviewees described the various ways in **which the eHNA process triggered new or different conversations with clinicians.** PABC reflected on the extent to which they 'needed' the eHNA, often describing how well-supported they were through treatment, with an underlying assumption that the eHNA was set up to support those more in need than them.

Yet, despite this variation on the extent to which PABC felt the eHNA was relevant to them personally, PABC interviewees who remembered the eHNA all appreciated the opportunity to discuss non-clinical concerns in the hospital setting. This was best summarised by one PABC who felt that she needed little additional support but reported that the eHNA **helped validated her as a person, beyond being part of the 'machine of oncology'.** This was echoed by another PABC interviewee who described how talking about wider issues was valuable in itself.

"Just having someone spend time to talk with you about those things is very helpful, even if the result is that nothing needs to be addressed." PABC interviewee

In this way, whilst debates over timing and process remain, the overwhelming feedback from the PABC interviewees was that the eHNA provided a worthwhile and welcomed opportunity to have different conversations, which helped **shift the focus away from cancer and back to them as a whole person**.

Support for friends and family

PABC interviewees tended to feel that the people around them (e.g. family, friends and carers) had the information they needed whilst they went through their cancer care at Addenbrooke's. Often, they described their friends and family as focussed on the practical aspects of treatment, to help plan time off work to attend appointments or to provide care. In these instances, PABC interviewees tended to agree that the information from the hospital or sourced independently was enough to put friends' and families' concerns to rest.

"My family were quite happy to hear it second hand from me really. With the information we'd had, the booklets and from the hospital I was able to answer their questions.... They didn't have any problems." PABC interviewee



Given the evaluation did not directly interview friends and family this may not present the full picture; arguably friends and family might not take concerns to the person undergoing the cancer treatment. Nonetheless, there were no specific gaps in support for friends, family and informal carers raised through the evaluation.

Telephone clinics

Risk-stratified clinics reconfigured the pattern of follow-up care depending on the risk-level of the individual patient. The new clinics took different models – shaped by the requirements of follow up at a specific cancer site, PABC numbers and logistics. PABC interviewees who had experienced remote (telephone), Nurse-led follow up appointments identified **several benefits to the risk-stratified clinics**, outlined in more detail below.

Saving time and money

Stakeholder interviewees with a clinical background described how **risk stratified clinics reduced the number of times PABC visited the hospital**. They argued that this improved PABC experience, particularly by reducing the inconvenience of travel time and other costs.

"I think that from a convenience point of view, for both sides it was very good – compared to the inconvenience of going into hospital. And especially for someone like me who, fortunately the cancer seems to have been caught, so there's no 'how's it progressing?' or 'how long have I got to live?'" PABC interviewee

Feedback from PABC on the Prostate remote Nurse-led clinic was equally positive about the convenience of the process.

"Cannot fault the service. A very sensible alternative to what would be a very time consuming and costly hospital visit." Respondent comment

The Prostate clinic survey asked PABC clinic attendees to state the extent to which they agreed that it was **helpful to have fewer visits to hospital**. Of the 35 respondents, 77% strongly agreed; 23% agreed.

Reducing the emotional burden

Clinician interviewees reported that PABC often describe how waiting in hospital for follow up appointments brings back the memories (and associated distress) of when they were first diagnosed. As such, another benefit of remote follow-up clinics is to **reduce the potential trauma of a hospital visit.** This was described by one PABC who was relieved to have the opportunity for a phone appointment rather than have her 'mood lowered' by a hospital appointment.

"I was offered a telephone interview appointment... There are various benefits of telephone calls. You're likely to remember all the things you've noticed and want to talk about. And they're more relaxed. You get to that clinic, it's busy, you see



so many people, and it can lower your mood. I'm generally very buoyant but I've come out there feeling 'I'm so lucky, look at these poor people.' I found [the clinic appointments] quite upsetting." PABC interviewee

Satisfaction with Nurse-led care

Both the Prostate and Breast clinic feedback surveys asked PABC to consider their overall satisfaction with their care in the risk stratified clinics. With 52 responses, PABC feedback at the Breast site was generally very positive. Responses against the specific questions are presented in detail in Figure 6-1 below.

Over 95% of PABC agreed or strongly agreed with the following statements:

- I had enough time during the consultation to discuss fully all that I wished to 98% agreed
- I felt that my needs were addressed confidently during the consultation 98% agreed
- I was involved and informed in decisions about my care 98% agreed
- The Nurse / healthcare professional was knowledgeable and able to answer all my questions 96% agreed.

With 35 responses, feedback at the Prostate site was equally very positive, as illustrated by Figure 6-2 below. In total, 100% of PABC respondents agreed or strongly agreed with the following statements:

- I felt informed about what to expect from the telephone clinic appointments following the discussion with the Nurse in clinic
- I had confidence and trust in the Nurse who contacted me for the consultations
- The Nurse was knowledgeable and able to answer all of my questions
- It was helpful to have fewer visits to the hospital.

The data indicates that PABC were satisfied with the new pathway and their experience.

PABC interviewees who did not remember the clinics were broadly receptive to the idea in principle, although suggested that **other people might prefer to talk face to face** or live so close to Addenbrooke's as not to experience inconvenience when travelling to the hospital.



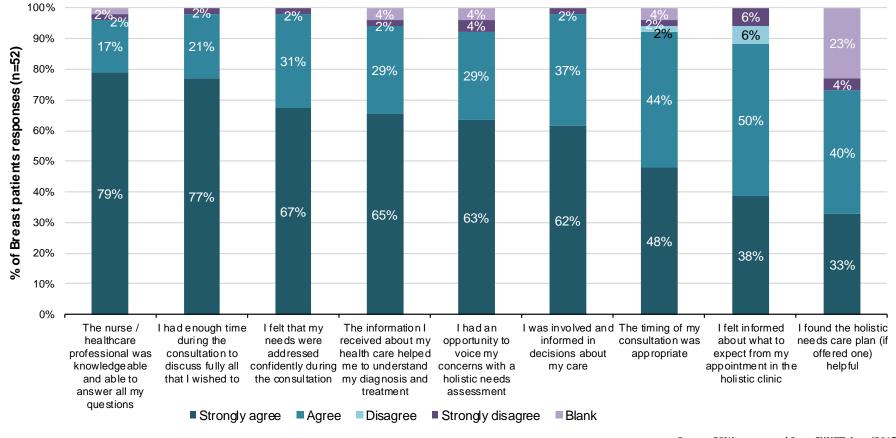


Figure 6-1: PABC feedback regarding the Breast cancer risk stratification process (N=52)

Source: SQW aggregated from CUHFT data (2017)



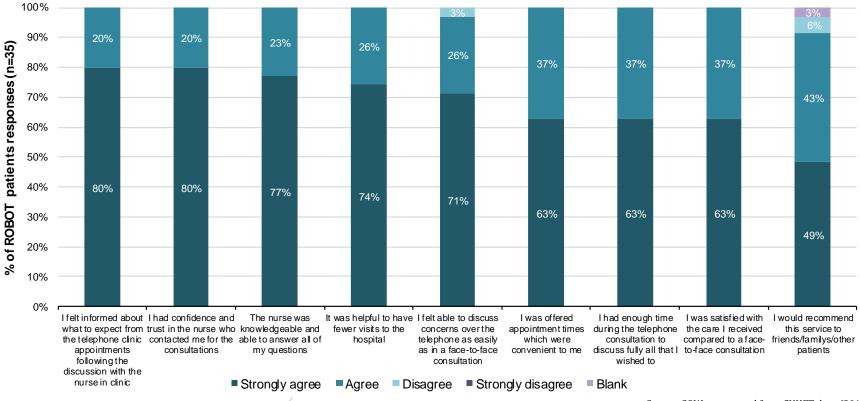


Figure 6-2: PABC feedback regarding the Prostate cancer risk stratification process (N=35)

Source: SQW aggregated from CUHFT data (2017)



Areas for future consideration

Increasing the profile of Care Plans and Treatment Summaries

All five PABC interviewees struggled to remember other aspects of the Recovery Package. For example, no interviewees could remember attending a HWB event, or having a Care Plan or Treatment Summary.

Their experiences are likely to correlate with the practice of their cancer site. Nonetheless, the following quote from a PABC indicates how having a summary of conversations was useful, particularly given how difficult she found it to remember details in appointments.

"Initially when I went for my appointments I was recording them. I asked the Consultant's permission first [and] when I did it really helped me. Recording is useful – in the heat of the moment you can forget what you said. Usually I'm fairly organised and I have a list of questions ... [but this is a chance to] review what was said – it was reassuring. At the time of the cancer diagnosis, your mind is all over the place. You don't know what your prognosis is and how long you've got. Potentially you could die from this thing. So, it's good to record it – your mind doesn't absorb stuff at the time, so you can go back and review it. And it's easier to do that rather than make notes." PABC interviewee

It is not possible to comment on the impact of the Care Plans and Treatment Summaries. However, the quote above indicates value in a process to aid PABC to remember the details of treatment and appointment discussions.

Considerations for the future

Given the issues engaging PABC within the evaluation, the clinic feedback data was hugely useful to building a picture of the impact. Continuing to survey PABC as they experience risk stratified follow-up care will be useful, to assess the impact on and experience of PABC in future.

Outcomes for the cancer workforce

By supporting CUHFT staff and volunteers (primarily through tailored training courses), the MICCP worked to equip a core of the cancer workforce with the tools and competencies needed to deliver new models of care. Recognising the scale of the challenge, operating at a large tertiary hospital, the MICCP was intended to sow the seeds of learning to generate longer term culture change.

"The Learning & Development programme is to support culture change - so staff move away from a paternalistic approach and so patients can be empowered to self-control their care... they can share the responsibility and decision making."

Stakeholder interviewee



This section explores the impact of MICCP-commissioned training courses for Addenbrooke's staff and volunteers upon their attitudes, knowledge and confidence, and the extent to which any new learning was put into practice. The data is primarily taken from the training feedback forms (designed by the MICCP team) completed before and after each training session, supplemented by the stakeholder survey and interview data.

Re-evaluating relationships with PABC

Training evaluation forms asked participants to reflect on whether (and the extent to which) the training had altered their attitudes and beliefs when delivering cancer care. The responses (from the Self-Supported Management course) were overwhelmingly positive, with **attendees reporting the training to be 'mind altering.'**

In particular, attendees described how it **led them to re-evaluate their relationships with PABC**, so that the PABC set the agenda and took ownership of their own plans. They also described the specific skills required to have new conversations, for example **how to phrase questions and be self-reflexive**, **considering the situation from the PABC's point of view**.

"It has helped me to recognise importance of establishing the patient's own viewpoint and confidence levels, and then facilitating/collaborating on an action plan. Levels of activation differ – it is essential to establish where [each] patient is."

"[I'm] more aware of how the way we phrase questions, how our questions are perceived by patients. Importance of shifting conversations away from 'I' towards what is important for the patient."

"This has encouraged and motivated me in the importance of self-management. The training has increased my knowledge and confidence in changing my approach in consultations, exploring with patients what is important to them as individuals, setting [the] agenda and goal setting."

Source: REACT

This sense of a **new relationship between clinicians and PABC** is illustrated by the following chart which incorporates feedback from the Self-Supported Management training. Participants were asked to what extent they agreed with two indicators that explored the sense of equality between staff and PABC, both in terms of expertise and in terms of shared responsibility around decision making.



Number of staff responses (n=21) 20 ■ Not sure Strongly Disagree 9 15 Disagree 12 ■ Agree 10 ■ Strongly Agree 5 Q1: Pre-Training Q1: Post-training Q2: Pre-Training Q2: Post-training

Figure 6-3: Changes in perspectives through cancer workforce training

Q1: The person and the health care professional are equals and experts

Q2: The person and the health care professional share responsibility for decisions made during the consultation

Source: SQW aggregated from CUHFT data (2017)

The chart illustrates how the sense of equality increased over time. Before the first training course, 33% (n=7) of respondents agreed that professionals and PABC were equal and expert. By the end of the course, 81% (n=17) agreed or strongly agreed with this statement.

Knowledge and skills

The pre- and post-training questionnaires explored the extent to which training had a positive impact across 13 indicators for the 21 trainees. All indicators showed a notable increase in workforce self-assessment of confidence, skills and knowledge after the training. The following table ranks the indicators according to areas where attendees reported the greatest improvements in confidence.

Table 6-3: Impacts reported from the Self-Supported Management training

Indicators	Ranking of improvement in confidence
How confident are you to you to do self-management support with your clients/patients	1
Help patients to develop the skills needed for effective self-management	2
Collaborate with patients in setting personal health and wellbeing goals & action plans	3
Recognise and explore ambivalence	4
Undertake joint problem solving to support patients to meet their goals & action plans	5
Jointly agree how and when progress will monitored	6
Sign post people to health and wellbeing programme/clinic/education/events	6
Jointly agree the purpose of the consultation	7
Know the person's priority and their expectation	8
Adopt a culture of continuous service improvement	8
Explore with the person how their condition affects their life	9
Identify all the person's concerns	9
Introduce and discuss the areas of diet and exercise	9

Source: SQW aggregated from CUHFT data (2017)



Prior to training, participants had the lowest confidence for the following two indicators – which rose the most out of all indicators by the end of the training:

- Self-management support with your clients/patients
- Help patients to develop the skills needed for effective self-management.

Prior to training, attendees were the most confident (both in mean and median comparisons) in exploring with patients how their condition affects their life; identifying all of the person's concerns; and introducing and discussing areas of diet and exercise.

Impacts upon practice

Training feedback forms asked participants to reflect on whether they anticipated the training would impact upon their practice. Again, feedback was broadly and consistently positive. Attendees described the different ways they anticipated the training to impact upon practice, for example how it would shape the way they set the agenda for consultations, help them to avoid having a 'fixed mind' and encourage them to use a greater number of open questions 'to engage patients to find their own solutions and goals'.

The stakeholder survey asked respondents who had attended a MICCP commissioned training course to consider the extent to which they agreed with the following statements:

As a result of the training:

- I am able to engage with PABC more effectively
- I feel more empowered to provide support to PABC
- I feel more confident in asking PABC about their needs.

Of the 18 respondents that answered this question, 10 were hospital volunteers and support staff – all of whom agreed or strongly agreed with these statements.

Of the eight medical and clinical professionals that answered this question, five agreed or strongly agreed, with one respondent detailing how the training would be particularly helpful when dealing with distressed patients. The remaining three medical and clinical professionals either disagreed or said the statements were not applicable due to having previously acquired the relevant skills through other training or their day to day experience.

"As a senior Nurse I was already able to do this, having worked in cancer for many years and had access to other higher-level training, and skills training i.e. Advanced Comms, Myers Briggs, Clinical Supervision, Mindfulness, Health Coaching in another setting." Stakeholder survey respondent

This suggests that **the training was particularly pitched well to support staff or volunteers** who had not participated in similar training in the past.

Whilst stakeholder interviewees were broadly positive about their abilities to put the training into practice, they did outline some **barriers to doing so**. These included **workloads, constrained**



staffing levels and ingrained ways of working of their immediate teams. One interviewee described feeling 'disempowered;' the sense that they had benefitted from the training but were prevented from putting the learning into practice by **wider structural issues** at the time.

Improved capacity for medical stakeholders

Beyond the workforce training, there were a number of other ways in which the MICCP was anticipated to impact upon the workforce. Possibly the most significant way was through risk stratified follow up care.

Stakeholder interviewees felt that the **new telephone clinics helped free up their capacity**, allowing them more time to focus on providing care. It also reportedly relieved some of the general stresses of the workplace – exacerbated by capacity squeezes - and gave them the space to develop their own skills through training and reflection to help fill their own knowledge gaps.

"By doing risk stratification and starting telephone clinics, staff don't have to worry about a backlog of patients and emails that are entering the system – they now have 80 patients that need to be seen this month compared to 1000 patients for face to face with 3-6 month waiting times." Stakeholder interviewee

"The time freed up by risk stratification has created an opportunity for us to be able to go into certain sessions like psychological assessment skills and communication training, which is really good as it motivates staff. There is an opportunity to fill the gaps in your knowledge." Stakeholder interviewee

Outcomes for cancer services

The MICCP embedded a wide range of new processes and systems to improve the overall structure and effectiveness of cancer services at Addenbrooke's Hospital. The MICCP tackled processes ranging from reworking the template for new patient clinics, setting up Exercise Referral processes and informing new system builds into EPIC. Alongside this was the workforce development plan, upskilling a core of the cancer workforce with the knowledge, skills and confidence to lead a shift in culture, where PABC are partners in their care.

Despite – or perhaps because of – these multiple workstreams, measuring the impact of the MICCP upon cancer services is challenging given the complexity of the system and other factors affecting service operation. This section refers to stakeholder survey data and interviews, to understand, where possible, the impact of the MICCP upon cancer services.

Information flows

A MICCP objective was to improve the flow of information across cancer services. The nature of this varied and included several Recovery Package elements that depended on an EPIC build to support them. Stakeholder interviewees reported an **adjustment period**, as the workforce learned how to use the **new IT systems and processes**, particularly in terms of how to correctly submit eHNA and Care Plan data so that submissions were 'locked' and recorded.



However, the wider changes to deliver the MICPP Recovery Package were viewed positively by a range of stakeholders. Interviewees particularly welcomed:

- The ability to **view all concerns** relating to the individual PABC in one place
- The ability to **share information across staff and partners** (e.g. Exercise Referrals being passed on to Community Programmes)
- The development of the MyChart application for PABC to utilise at home.

Better coordination of patient pathways

Interviewees described how the MICCP had improved coordination of PABC pathways in a number of ways, including:

- Nurse-led clinics meant that low-risk cohorts of PABC received **appropriate follow-up** care (**'freeing up' clinician time** to focus on higher-risk PABC)
- Exercise Referrals now have a streamlined process across a wide range of partners, from both within and external to Addenbrooke's, sharing information in a coherent and accessible way
- Recovery Package elements such as eHNA and Care Plans on EPIC mean that the cancer workforce have greater **awareness of individual PABC journeys**
- eHNA conversations mean that Nurses can signpost PABC to relevant information across a range of needs.

"A couple of times clinicians have come [into the Macmillan POD] and said they're expecting patients to come in [and so] asked what resources they needed in advance and worked through a list. A couple of Nurses came in and said 'these are the top five concerns for my patient. What would you suggest I take back to them?" Stakeholder interviewee

The stakeholder survey asked respondents to consider the extent to which they agreed that, as a result of the MICCP, there was better coordination of pathways across organisational boundaries. Across all respondent groups, just one third (nine out of 27) of respondents agreed or strongly agreed that there was better coordination of pathways across organisational boundaries for PABC as a result of MICCP. Whilst just one respondent disagreed with this statement, this may indicate scope for further improvements in coordination. This may be realised as the roll-out of MICCP continues.

Improved relationships between PABC and healthcare and support services

One of the overarching objectives of the MICCP was to inspire **wider culture change** at Addenbrooke's, whereby the cancer workforce and PABC work collaboratively and in partnership throughout treatment and follow-up care. As feedback from the workforce development training shows, attendees were encouraged to think through their relationship with PABC and how to make changes to their daily practice through new conversations and active listening.



However, putting learning into practice can be difficult in the 'business as usual' environment. Achieving culture change will be a much **longer-term objective and beyond the timescales of this evaluation.**

What is possible to assess, however, is the way in which **relationships between PABC and the cancer workforce improved as a result of the MICCP in the short term**. PABC were positive about the impact of the eHNA on their relationships with Addenbrooke's staff, and how this differed to their previous experiences over several years of cancer care. PABC on five-year check-ups reported how the eHNA was their first opportunity to speak to a member of the cancer workforce about other concerns, and welcomed these person-centred conversations.

The stakeholder survey asked about the extent to which respondents agreed that the MICCP had improved relationships between PABC and healthcare and support services. Across all respondent groups, 12 out of 27 respondents agreed or strongly agreed that there are improved relationships between PABC and healthcare and support services (with no respondents disagreeing with this statement). The evidence suggests that the eHNA was an important tool to drive this wider culture change.

These findings indicate early progress towards broader culture change.

Improved capacity

By improving the coordination of PABC pathways and facilitating the flow of information across PABC and the cancer workforce, the MICCP aimed to improve the capacity of the cancer workforce. This objective was critical given the rising demand for cancer services.

One of the core ways in which the MICCP impacted capacity was through risk-stratified follow up care. Stakeholder interviewees explained how risk stratification of PABC helped the cancer workforce to be clear about PABC pathways, and 'freed up' clinician time as low-risk PABC received Nurse-led follow up care. This 'freed up' time was critical for accommodating the new waves of people receiving cancer diagnoses:

"MICCP and similar work creates capacity within the existing cancer services for the increasing number of patients, both being diagnosed with cancer and the increasing number of survivors." Stakeholder survey respondent

The pathway mapping element of risk stratification was time consuming, but the newly commissioned clinics were well received and valued by both stakeholders and PABC that experienced them.

"And it's taken as read [that during hospital appointments] they always get behind and [the clinics] are oversubscribed through no fault of their own, they have to get the people in and there are too many [patients to care for]. So, if they're able to free it up by speaking to me on the phone then I'm fine by that."

PABC interviewee



Outcomes for the cancer system

Workstream 4 was designed to engage services across the wider cancer system directly in the MICCP, through targeted engagement of wider partners and by working specifically with GPs to roll out Treatment Summaries. Through a series of strategic and pragmatic decisions, the MICCP delayed this tailored engagement workstream, focussing instead on engaging services through specific Recovery Package strands. Specific areas of successful engagement included:

- The success of the **Exercise Referral** process encouraged other nearby local authorities to employ instructors, thus supporting even more PABC across East Anglia
- Key partners and organisations were engaged at an early point through the MICCP for the two HWB events which occurred in 2015/16
- The MICCP team supported partners to meet mutually beneficial objectives. For example, by assisting the Exercise Referral lead to develop a business case to secure external funding
- The Macmillan team influenced their strategic partners during other meetings and contact. This led to **greater clarity** amongst key stakeholders about MICCP activities at the Trust, as well as opening up new contacts involved in integrating cancer care at other Trusts
- The Macmillan GP was involved in **designing and trialling the Treatment Summary** at the Colorectal site, which informed a template which will be accessible to other GPs once rolled out further.

GP awareness of MICCP

The GP survey asked GPs to what extent were they aware of, and felt clear about, a range of MICCP activities. The seven responses suggest that GPs are more aware of specific components of the Recovery Package than the umbrella term of 'Recovery Package'. In other words, GPs report more awareness of Care Plans, Treatment Summaries, Exercise Referrals and HWB events than of the Recovery Package as the overarching toolkit. The element which had lowest recognition was the eHNA³⁷ with four of the seven GPs stating they were not aware of it.

³⁷ One GP didn't indicate their awareness of the eHNA as the survey did not force responses to each question.



Considerations for the future

Once the trial of the Treatment Summary at the Colorectal site is complete – and assuming there is capacity within the MICCP team - there is an opportunity to draw upon the Macmillan GP's networks and influence to roll out Treatment Summaries across other cancer sites. A key enabler will be the work of the EPIC team to build a template for the trial.

Raising GP awareness of the MICCP could take place via a number of routes. One opportunity is to use the Cancer Alliance to secure greater GP engagement and roll-out of MICCP elements moving forward. Another is to report the benefits for GPs, to GPs by GPs, to encourage their buy in, with a focus on how MICCP improves PABC experience and care – and how it can enhance the care that GPs provide. It is of course necessary to be mindful of the continuing constraints in primary care and ensure GP burden remains minimal.



7. Evaluation findings – key learning emerging

Any assessment of 'what worked and why' must take into account the wider operating context, to ensure that evaluation learning is relevant and replicable to other sites. This is particularly the case for the MICCP, where the setting is a large, tertiary hospital. With established systems and processes, and not to mention the wider resourcing issues facing the NHS, what happened at Addenbrooke's on a daily basis dictated what was achievable through the MICCP. Short term MICCP delivery was very much affected by the wider context.

A few **key barriers** emerged during programme implementation. For example, Consultants varied in the extent to which they agreed with the principle of risk stratification, depending on whether they wanted to 'give up control' of the PABC under their care. Moving to a paperless hospital system meant that the EPIC build prioritised critical requests, pushing MICCP-related adjustments lower down the priority list. Turnover of key staff triggered gaps in resourcing Recovery Package components or meant that pathway mapping had to start afresh, to engage and persuade new colleagues to continue with work set out by predecessors. Winter pressures led to all non-emergency meetings being cancelled. All of these conditions were exacerbated by the **sheer scale of Addenbrooke's**, as well as an MICCP office move out of the main hospital building, making it more difficult to casually bump into, and get an answer from, key individuals. The movement of the team outside of the main hospital building also risked the MICCP team being seen as 'separate'.

"Never under-estimate the value of a corridor conversation". Stakeholder interviewee

In summary, **MICCP required sustained momentum**, keeping the programme high up the priority list of the staff and partners who were crucial to the success of each element of it. Based on all strands of the evaluation, the following learning is aimed at other sites looking to integrate cancer care in a similarly fast-paced and complex environment.

Navigating the operating context

This section contains five ways in which the MICCP team maintained momentum in a complex and ever-changing operating context of a busy tertiary hospital.

Prioritisation of quick wins

The initial MICCP objective was to risk stratify all cancer pathways; however, with 23 different pathway sites, **the team had to prioritise**. For risk stratification, they included any sites which had already started pathway mapping, as in the Breast site, and engaging with interested staff and clinical leads.

For implementing the Recovery Package, they targeted eHNA at sites which had the **resources and physical space** to deliver it, such as the Breast site, which had both a dedicated volunteer and a more private waiting room for the conversations. Another quick win was to focus the work around



Treatment Summaries at the Colorectal site, as the Director of Cancer Services was working within the team and helped to embed the work within the site.

Given the breadth and depth of the MICCP scope, focussing on a few tumour sites gave the team the opportunity to achieve progress against some key objectives. By prioritising who to work with, where to work and the specific area of focus, **the MICCP was able to trial and test pockets of activity** across the cancer directorate and generate important learning to inform wider roll out.

Fluid approach at a time of capacity squeezes

One of the other benefits of rolling out pockets of risk stratification and Recovery Package activity at different sites was that the MICCP team was able to **quickly re-prioritise and change focus**, depending on where the momentum was (or wasn't) at that particular time.

As well as **reliance on key people, the MICCP team was also dependent on some internal systems** and processes. Delays to critical decisions or responses led certain strands of work to grind to a halt, such as the time between submitting CMRs to the commissioning board and having the submissions approved. In response, the MICCP team worked flexibly, picking up different workstreams depending on the opportunity at hand. With so many balls in the air, there was always another to catch when something temporarily dropped.

This approach is reflected in the different stages of implementation of risk stratified care and the Recovery Package across different cancer sites. Whilst this pragmatic approach made it difficult to read across the data from an evaluation perspective, it was a proactive response to implementing a major change programme in a busy hospital setting.

A project team with a 'can do' approach

The success of different MICCP elements was largely **dependent upon the amenability, cooperation and energy of the key members of the cancer workforce** (including clinical and support staff and volunteers) and partners. Recognising the pressures facing these stakeholders, not to mention their competing priorities, **the MICCP team worked to facilitate their engagement**, regardless of the scale of the task involved. This could involve the MICCP team influencing at senior stakeholder level, or re-writing a letter template to invite PABC to the new clinics. Sites particularly appreciated the administrative support offered by the MICCP team during pathway mapping, as well as the support they received to complete and submit the CMR form to CUHFT's internal commissioning board.

This required hands on project management and strong working relationships in order to keep the process moving, and there are implications for the make-up of the project team. The ability to **work flexibly and a willingness to pick up necessary tasks**, even if seemingly mundane or basic, proved crucial to fill capacity gaps and maintain momentum.

Ongoing work to influence and negotiate

Given that one of the longer-term objectives of the MICCP was culture change, the MICCP team worked to raise the profile of the programme across the Cancer Directorate. Being able to influence and negotiate with key stakeholders of all levels was key.



The MICCP team **networked through formal channels** within Addenbrooke's via the Steering Group meetings and the Cancer Patient Partnership Group. This served to keep the programme on the agenda and embedded strategically. The team also **networked externally**, attending meetings with the Cancer Alliance and meeting with key stakeholders such as the Macmillan GP and commissioners from the CCG.

Influence and negotiation also took place effectively outside the formal channels of steering groups and meetings. The MICCP reported how **chance conversations** with clinicians in a corridor or canteen could trigger a potential opportunity at a new site. This was especially important given the limited capacity of clinicians to respond to emails. The small, dedicated MICCP team maximised the programme's profile by **encouraging engaged stakeholders, such as CNSs, to champion the work** within and across cancer services. In these ways, every conversation was an opportunity to influence, spread the message, create a body for change, and raise the profile and purpose of integrated cancer care.

Be realistic about the pace of change

The scope of the MICCP changed as the team built up their experience of delivering it. The wider context and pressures meant that the MICCP team revised their expectations of what was possible to achieve over the course of the programme. **Being realistic about the pace of change** – and recognising the scale of the challenge – was helpful to manage expectations of what was possible and celebrate success when it happened. As one stakeholder suggested, the MICCP is a critical catalyst to integrating cancer care, but not the end of it.

"I'm hopeful [MICCP] will meet its objectives - but it will take longer than this project. This is just the beginning. We might be getting to the end of the beginning but it's not the end. And through the passion and dedication of people that work in cancer it will continue, it will progress." Stakeholder interviewee

Specific areas of learning

As well as the behaviours and broader approach outlined above, the evaluation reveals other key learnings to consider when integrating cancer care. These include the importance of:

- Engaged clinicians at site level, with the authority, capacity and skills to unite and enthuse colleagues around a shared vision and new ways of working
- Volunteers in supporting elements of the process, most specifically in providing a
 dedicated resource to hand out iPads and support with non-complex information giving.
 This learning has informed the Patient Navigator role, which will provide that capacity via
 a consistent and paid role moving forwards
- **GP champion(s)** to trial and test specific elements and to disseminate information in an appropriate way to other GPs, providing peer credibility and understanding of the context in which they operate
- A **fully resourced programme team** across the period of delivery, able to pick up tasks across multiple cancer sites and of varying degrees of complexity



- Prioritising and trialling new ways of working on a pathway by pathway basis (as seen
 by Treatment Summaries at Colorectal site; eHNA at Breast site; and telephone clinics at
 Prostate site), to generate learning, rather than attempting to drive through all activities at
 the same time
- Collecting meaningful PABC experience data at every opportunity where appropriate
 e.g. risk stratified clinic feedback, and using this to inform revisions and refinement to the
 model
- **Considering IT implications and build these into the work plan,** specifically in terms of prioritising specific activities or workstreams.



8. Building the business case

Introduction to the economic assessment

The economic assessment uses information from the risk stratification and re-design process as recorded in CMRs, along with cost data. As the MICCP is still in delivery, the economic assessment includes an estimate of the, as yet, un-identified (not yet realised, but anticipated) savings also³⁸.

The assessment includes scenarios to explore potential variations in the impact of the un-identified savings, e.g. high, medium and low scenarios, with an optimism bias set at $5\%^{39}$ in the CMR estimates⁴⁰.

Specific considerations regarding the economic assessment approach are outlined in more detail below.

- **Costs:** The costs were determined as the Macmillan funding for the programme. However, as the HWB events are an important part of the re-design which have been prioritised (and would need to be paid for) going forward, the cost of events is considered as an additional requirement to maintain the new pathways and support recovery.
- **Outcomes**: The CMRs detail the new and old pathways, including numbers and costs along with estimates of risk stratification, where appropriate. The old pathways were used as the comparator for the new pathways.
- **Scope:** We have estimated the impact in areas yet to be risk stratified and re-designed. Pathways not due to be reviewed as part of the process were out of scope for this work.
- Perspective: The analysis took into account the costs to the programme and savings to the
 provider, and assumed the provider would need to take on costs of continuing the work
 going forward. We covered a Trust perspective in our assessment, but were unable to
 consider changes in other health or social care costs, such as costs associated with PABC
 interactions with GPs.
- **Timescales**: We set an analysis **timeframe of five years** moving forwards (9 years overall) to reflect the fact that benefits accrue over the longer term.

The following diagram illustrates our approach.

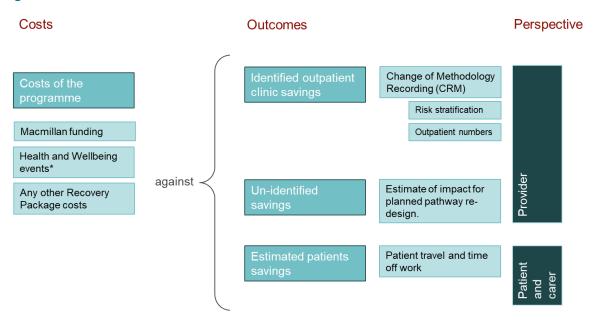
⁴⁰ Data on risk stratification and attendances where the CMRs have been implemented may help assessing the robustness of estimates.



³⁸ It is expected this will include mapping outpatient data to pathways to estimate the proportion which has not been, but will be, redesigned and risk stratified.

³⁹ Optimism bias can provide a correction for the uncertainty around the available evidence, through an increase in the programme costs and a decrease in the financial value of identified benefits.

Figure 8-1: Elements of the Economic Assessment



^{*} This is covered in the above within the timescales of the programme but important to separately identify this as it is a key cost going forward to maintain the savings.

Source: SOW

Costs

The costs of the programme are the **Macmillan funding**. However, to maintain the new pathways and support implementation moving forwards, e.g. after Macmillan funding ends, the **costs** associated with the new clinics and Recovery Package are also considered in our analysis.

There is a **total cost of £586,568 to Macmillan for funding MICCP** over the period February 2015 to December 2018. This was financed through two grants: the first to cover the MICCP lead post, learning and development activities and some PABC engagement; the second to cover further project staff, further PABC engagement and HWB events. Below shows the funding awarded:

Table 8-1: Breakdown of the Macmillan funding for the MICCP

Funding Amount
£185,942
£149,195
£106,876
£83,625
£17,000
£22,500
£21,430
£586,568

Source: Macmillan Summary of Investment



*Not in post for the full duration of the programme

Recovery Package

The ongoing cost of the Recovery Package includes two elements:

- Health and Wellbeing events
- Additional clinics and eHNA follow up appointments.

The cost of these are £17,000 for six HWB events annually and £166,400 for 800 additional clinic appointments (at a cost of £208 per appointment) for the pathways yet to be approved, as detailed in the "Living With & Beyond Cancer Service" document submitted to the CCG. It has been assumed that the cost for all the pathways is double this cost, at a total annual cost of £349,800 41 .

Benefits

The benefits considered are associated with changes in the pathways following the risk stratification process. The CMRs detail the current and the proposed clinics, including the numbers attending outpatient clinics based on retrospective data and the costs, along with estimates of risk stratification proportions, where appropriate.

In total, **15** cancer clinics have been approved, with a combined financial impact of £187,002 saving to the CCG. The following table shows the clinic costs associated with caring for patients under these new pathways.

Table 8-2: Clinics start dates, costs and anticipated savings

Speciality	Before	After	Saving to CCG	Date first patient seen
Prostate – ROBOT	£123,978	£74,568	£49,410	01/08/2016 ¹
Myeloma	£185,637	£137,377	£48,260	01/12/2017
Bone Marrow Transplant	£55,667	£30,811	£24,856	01/09/2017
Myeloproliferative Neoplasms	£123,323	£87,242	£36,081 ²	30/09/2015
Sarcoma	£29,926	£10,999	£18,927	29/10/2015
Glioblastoma	£123,519	£108,159	£15,360	14/01/2016
Acute Myeloid Leukemia	£32,304	£26,830	£5,474	Yet to go live
Lower Gastrointestinal – Anal	£67,722	£65,320	£2,402	01/01/2018 ³
Teenager and Young Adult - Late Effects (Haem)	£29,000	£27,552	£1,447	01/07/2017

⁴¹ This assumption is from CUH leads. Note, the cost is only doubled for the additional clinics and not the wellbeing events.



Speciality	Before	After	Saving to CCG	Date first patient seen
Teenager and Young Adult - Late Effects (Onc)	£17,504	£16,199	£1,305	Yet to go live
Breast – EoT			£0	03/06/2015
Gynaecologic – Ovary	£98,071	£103,984	-£5,913	Yet to go live ⁴
Breast-Metastatic	£112,281	£118,351	-£6,070	Yet to go live ⁵
Upper Gastrointestinal	£ -	£ 4,538	-£ 4,538	01/09/2017
Prostate (Onc Hormone ⁶)	£ -	£ -	£ -	01/08/2017

Source: CUHFT's CMR data 2018 and Living With & Beyond Cancer Service

Economic Analysis

Scenarios

The CMRs submitted to date represent half of the pathways and thus are expected to reflect half of the total potential saving. There is however uncertainty in this assumption, and to reflect the uncertainty three scenarios have been developed: high, medium and low:

- The **medium scenario** reflects the expected savings from the remaining 50% of pathways to equal the identified savings from the approved pathways, i.e. 50% of possible savings are yet to be identified, a total saving of £464,000 per annum
- The **low scenario** reflects a lower rate of savings from these pathways where they contribute 20% less to the overall savings, a total saving of £417,600
- The **high scenario** reflects a higher rate of savings from these pathways, where they contribute 20% more to the overall savings, a **total saving of £510,400**.

These scenarios represent the 'yet to be identified' savings (e.g. savings expected if all the outstanding (not yet costed or approved) clinics come live, excluding existing clinics) to be in the range of £185,600 to £278,400. This range is after removing the £232,000 of identified savings from those pathways that have already gone through the CMR process.⁴²

⁴² The 'as yet' are the 50% of pathways/expected savings they have not yet quantified through a CMR. It is an assumption based on CUHFT expectations. The £232k is the proportion quantified already.



82

¹ There are two clinics here and for the purpose of modelling the impact we have used the latest date as the ultimate go live; 05/05/2016 (Transitional clinic) and 01/08/2016 (Telephone clinic).

This is based on a revised saving to the CCG after the CMR and the after cost has been reduced in line with this saving figure. ³ There are two clinics here and for the purpose of modelling the impact we have used the latest date as the ultimate go live; Nurse-led

Follow Up (01/12/2017) and Nurse-led telephone (01/01/2018)

⁴ There are two clinics here and for the purpose of modelling the impact we have used the latest date as the ultimate go live; Nurse-led (20/06/2017) and Nurse-led telephone (yet to go live).
⁵ There are two clinics here and for the purpose of modelling the impact we have used the latest date as the ultimate go live; Nurse-led

⁽yet to go live) and Nurse-led telephone (01/04/2018).

⁶ This clinic had already gone live so there is no before or after data available

Future efficiency saving profile

The savings identified are based on the early review of pathways. It is anticipated that once clinicians and PABC feel comfortable with pathways and the new ways of working become embedded, **efficiency savings** can be realised, reducing the number of face-to-face appointments needed even further. This in turn will increase the savings to NHS commissioners.

Results

In all scenarios except the low (without efficiency savings) the ROI is over 1.0, where for every £1 spent there is £1 of benefits, with payback periods from 5 years to 6 years. For the low scenario with no efficiency savings there is a small budget impact of £30,804, which is the additional budget required to finance the programme under this scenario.

Economic assessment statistics from the scenarios

Metric	Low	Medium	High		
With no efficiency savings					
Net Present Budget Impact	£30,804	-£210,719	-£452,242		
Overall Financial Return on Investment	0.99	1.08	1.16		
Payback period	-	6 years	5 years		
With efficiency savings of 5% p/a					
Net Present Budget Impact	-£453,850	-£745,866	-£1,037,882		
Overall Financial Return on Investment	1.16	1.27	1.37		
Payback period	6 years	5 years	5 years		

Source: SQW economic assessment calculations.

The medium scenario is considered the most realistic scenario, and the following figure shows the cumulative costs and savings over the period. This shows that the medium scenario cumulative savings are higher than the cumulative costs from 2021; with additional 5% efficiency savings this is achieved in 2020.



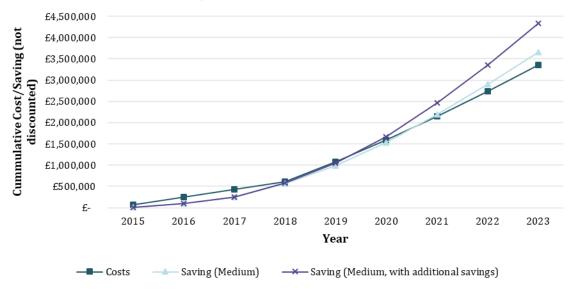


Table 8-3: Profile of costs and savings for the medium scenario

Source: SQW analysis

The number of patients attending CUHFT's Cancer Division increases year on year and the modelling of the costs and savings includes an assumption of 7% growth in activity per annum. If the MICCP was not implemented the current costs would continue to grow year-on-year in line with patient numbers.

The following figure shows the cumulative net budget impact of both medium scenarios, which save money in the long term so hence have a negative budget impact, against the estimated 'business as usual' costs if no changes were made and clinics and costs were allowed to grow in line with patient numbers⁴³. This shows cumulative costs are expected to rise by over £7,000,000 by 2023 without these changes, to over £1,700,000 per annum in 2023.

This starts from a 2015 baseline and assumes that no risk stratification has taken place (either during the MICCP or in subsequent years). In addition, it also assumes that all new clinics go live, alongside the existing risk stratified pathways. This may be an unrealistic position as there would need to be extra capacity to deal with this growth, but it highlights how the clinic changes are tackling both financial and capacity issues.

 $^{^{43}}$ This calculation is based on an estimated total cost for all pathways of £2,479,000. This is based on the total current cost from the CMRs of £999,000 and a percentage saving of 19% applied to the identified overall saving of £464,000.



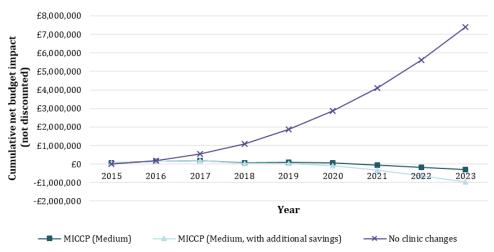


Table 8-4: Profile of net present budget impact, medium scenario (including 5% efficiency savings) versus no MICCP or other risk stratified clinics

Source: SQW analysis

Summary

The **programme** is expected to make a return on the investment in all but one scenario. However even in this scenario the overall financial position is better than had there been no change in pathways (e.g. no programme implementation), as the cost and the capacity requirements would grow due to increasing cancer patient numbers.



9. Conclusions

Contextualising the MICCP

In the past 20 years, the numbers of registrations for newly diagnosed cases of cancer in England have increased significantly. By risk stratifying pathways of care and embedding elements of the Recovery Package, the MICCP vision was to ensure that PABC received the right care at the right point in their cancer journey, alongside appropriate and relevant information and support for self-management.

"[The vision is] that anyone accessing cancer services through any door in this organisation has the same level of experience, that all our staff feel resilient enough to cope with what they're seeing and they pass that onto their patients. And that all patients have access to eHNA and, following that, they have good communication and relationships with us so they can raise their concerns and respond to us, that there is good dialogue around the best pathway for them to follow through treatment, and then there's a safety net when they get to the end of active treatment, and for the times when they're self-managing. They're out there on a tightrope, but it's OK, as they have a safety net underneath them."

Stakeholder interviewee

The process of integrating cancer care at Addenbrooke's was a **hugely ambitious goal**, particularly within the three years of the MICCP-funded lifetime⁴⁴. The breadth and depth of the full MICCP programme was exhaustive and any one of the four workstreams could have comprised a programme of activity in its own right. This indicates the size of the MICCP ambition and the scale of the challenge, particularly in an ever-changing environment such as Addenbrooke's and in the context of severe demand and capacity pressures facing the NHS.

This wider context generated a key learning point from the evaluation: **managing expectations of the pace of change in a busy tertiary hospital is vital.** The MICCP has to be assessed against the extent to which it has taken Addenbrooke's on the journey to risk stratification and implementation of the Recovery Package, and it will continue as an ongoing process into future.

Implementing change in a fast-paced environment

Attempting to realise whole-system change has required a range of activities and influence at all levels across the system. The MICCP team 'rolled up their sleeves' and pushed forward multiple streams of activity.

The risk for the MICCP is that this has been interpreted as a fragmented approach to delivery, given that risk stratification and Recovery Package implementation varied across sites. However, the findings indicate that this approach was in fact a strategic and pragmatic response the wider operating pressures facing the MICCP.

⁴⁴⁴⁴ By comparison, Ipswich Hospital, a local site which had successfully implemented risk stratification and Recovery Package activities, was a smaller trust and had seven years of funding to deliver it.



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The flexible, adaptable MICCP approach meant that the **team were able to generate 'quick wins,'** to trial risk stratified clinics and Recovery Package activities. These quick wins were showcased amongst other cancer sites internally, and generated learning to refine implementation at new sites. It has meant that the MICCP team could adapt their strategy according to the wider operating environment and keep up the momentum required to make change happen.

The impact of the MICCP

Despite significant disruptions to the momentum of delivery, the MICCP made good progress against several key workstreams, having a positive impact against key indicators, outlined below.

The MICCP in numbers

- 20 risk stratified pathways commissioned across Addenbrooke's cancer sites; of these, 18 are live and two waiting to go live
- New Exercise Referral scheme implemented, with 83 referrals
- 843 eHNAs undertaken
- 666 Care Plans developed
- 60 Treatment Summaries provided
- Two Health and Wellbeing events held
- 21 members of the cancer workforce completed the Self-Supported Management training programmes.

Impacts on PABC

- Remote clinics helped PABC to save time, expenses and emotional upset associated with appointments at the hospital
- PABC referred to the exercise scheme felt more in control of their recovery and incentivised to exercise more in the future
- PABC who had an eHNA reported the sense of feeling listened to and described the different ways they played an active role in their recovery planning.

Impacts on staff

- The telephone clinics enabled staff to free-up their time, and improved capacity
- The training was well-focused and empowering for staff, who report that it changed their attitudes to the staff-patient relationship.

Wider system change

• Stakeholders and partners reported a well-managed and streamlined Exercise Referral process across a number of key stakeholders and partners



- The cancer workforce are having new conversations through the eHNA, considering the needs of the PABC holistically, with a sense of culture change beginning to emerge
- The programme is building the 'movement for change' through risk stratified pathways
- The resource from Macmillan 'pump primed' implementation of MICCP, which will now be sustained locally building on the momentum generated.

Barriers

There remain some areas where progress has been limited or taken longer than anticipated. The key barriers were:

- Systemic **capacity and financial pressures** facing secondary care and throughout the NHS moved the MICCP lower down the priority list during peaks in demand
- Culture change was not possible amongst staff who do not want to 'let go of control' of their PABC to allow Nurses to undertake follow up care for lower risk patients
- **Dependencies on external factors** caused time lags and delays, such as the IT infrastructure and internal commissioning processes
- The administration of eHNA was complicated by the introduction of new Macmillan administration steps. There was now a requirement to set a passcode before completing an eHNA. This administration setup had to be absorbed by the MICCP and Nurses. This proved a major barrier to delivery. This change was probably the biggest factor in the drop in the number of eHNAs completed
- Capacity and turnover within the MICCP team led to challenges in delivering against the work-plan
- The **broad and far-reaching scope of the MICCP** meant the MICCP team could be spread thinly across multiple activities and had to de-prioritise specific workstreams.

Looking forward

The MICCP is a key part of the wider strategy within CUHFT to improve cancer care and coordinate pathways, but there remains work to do at cancer site, service and system levels. It is encouraging that funding has been provided to help sustain the programme post-December 2018 following the end of Macmillan's funding, to enable it to operate on a 'business as usual' footing.

For the next phase of implementation, awareness of the scale of the challenge and the pace of change should help to prioritise the task at hand. The MICCP team need strategic support to stay engaged and motivated, particularly as they work to engage and motivate colleagues across the wider system. The team are being creative going forward, responding to learning about required roles and resources, re-writing job descriptions to include an inpatient focus. This proposed team structure for the business as usual service is illustrated in the following chart (green roles are Macmillan funded).



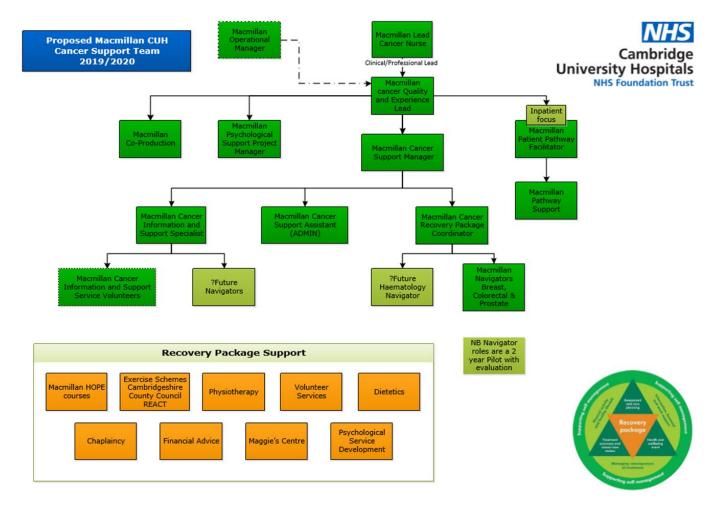


Figure 9-1: Proposed CUHFT Cancer Support Team Structure, 2019-20

Source: CUHFT MICCP organisational chart for 2018 and beyond



The Macmillan-funded three year programme (2015-18) has enabled the MICCP team to develop and test new ways of working, understand and address the barriers and build on the enablers. The MICCP provides the foundation on which CUHFT leads can build and sustain the model as business as usual moving forwards.



10. Recommendations

The recommendations below are based on the findings presented throughout this report, and are intended to inform local commissioning and delivery, as well as wider roll-out of the MICCP model.

Recommendations for local commissioners and the Cancer Alliance

Recommendation 1: Adopt a whole-system perspective to cancer care commissioning. Early indications are that Recovery Package interventions are more likely to achieve the desired impacts on PABC outcomes, system efficiencies and experience if implemented as part of a system-wide programme of change.

- Implications, including economic, should be considered at a system level, with impacts likely to be experienced at different levels by different partners.
- Consider knock on implications arising from implementing, and indeed not implementing, Recovery Package elements. For example, impacts on primary care, the voluntary and community sector, and social care, as well as impacts on the Trust and PABC.
- Considering the implications at the Sustainability and Transformation Partnership level may help to 'land' the programme at a strategic level across different partners who are not part of the core cancer workforce. This in turn may help to generate buy in and the programme to maintain momentum.

Recommendation 2: Recognise risk stratification and Recovery Package activity not as a means to generate immediate savings, but as a means to meet the challenges of increasing demands for cancer care in the future. Being realistic in terms of when financial outcomes will emerge, and also that it may not lead to cashable savings (as rising demand will fill the slots available), will be key. This evaluation has shown that the model does offer potential to better meet rising demand.

Recommendation 3: Be realistic about the expected scale and pace of change, given the system-wide focus of MICCP. All pathways are different, and it takes time to build clinician engagement alongside process development and implementation. Even clearly set out plans can be derailed by external factors and competing demands at site and organisation levels. Wider stakeholder relationships will be key moving forwards, including referring hospitals given the role of Addenbrooke's as a district general hospital and tertiary cancer centre.

Recommendations for CUHFT

Recommendation 4: Consider recruiting a formal clinical 'champion' to act as a high-level influencer across sites to unblock barriers and maintain momentum. Use 'champions' already implementing the new ways of working to share the benefits and encourage others at other sites, particularly when these champions have a clinical background and can influence other clinicians across cancer services. Particular messages to convey include:

 The positive responses to the Breast and ROBOT risk-stratified clinics, to illustrate the impacts emerging for PABC



- The positive PABC interviewee feedback about the eHNA conversations and how they are valued by PABC as a means to focus on them as a 'whole' person, in order to encourage eHNA completion
- The positive PABC feedback and testimonials referring to the benefits of exercise, and steps outlining the Exercise Referral process, to increase the number of clinicians that refer to the schemes.

Recommendation 5: Hold a strategic meeting with the EPIC team lead. A meeting with the EPIC lead to discuss and prioritise MICCP activities within their workload, to generate an agreed and phased implementation plan to align with their team's capacity, could usefully help to maintain momentum, ensure MICCP activities are planned into their workload, introduce reporting tools and build shared understanding amongst all relevant parties.

Recommendation 6: Consider how best to engage local GPs so they are ready for Treatment Summaries and are sufficiently knowledgeable about the Recovery Package, utilising the Macmillan GP's networks and expertise for support. This will help to secure buy in from GPs as key partners within the cancer care system, and will prove key to realising the next stage of the MICCP ambitions.

Recommendation 7: Engage internal and external commissioners to explore ways to minimise commissioning delays. This is with a view to ensuring that CMRs progress as quickly as possible, to minimise knock-on delays with implementation and to sustain momentum. We suggest that developing a schedule for when CMRs are expected to be developed (in conjunction with clinical leads at site level), and then agreeing this with the relevant director may help to minimise delays. Building flexibility into the corresponding implementation plan will also help to manage stakeholder expectations at site level and mitigate any delays emerging.

Recommendation 8: Continue with the training for the workforce. Consider delivering team-based training for sites (where possible and viable), or 'train the trainer' activities. Target medics to attend where they are seen to determine the departmental culture, by potentially adapting the timing of training and having clear materials to convey the benefits of attending. Continue to include volunteers in training, as a means to improve skills across the wider workforce and increase volunteer motivation, retention and engagement.

Recommendation 9: Use Care Plans to support continuity of care. Care Plans can help to support the continuity of care for patients when they are transferred between services. Supporting practitioners in the sites to correctly use the IT system that underpins the Care Plan process will be key to sustaining their use.

Recommendation 10: Continue the roll out of risk stratification within high priority sites initially. We suggest that these be selected either for their national strategic importance (e.g. particular focus of the Cancer Alliance) or for MICCP strategic importance (e.g. to trial a new form of clinic or risk stratify remaining pathways at engaged sites). Pragmatism (e.g. 'quick wins') will also usefully inform site selection.

Recommendation 11: Consider which elements of the Recovery Package implementation process should be standardised, and which can be flexed. Examples might include flexibility for PABC to complete the eHNA at home, providing volunteer or Patient Navigator support to those PABC less confident in using the app, or flexing the timing of the eHNA on a site-by-site basis.



Monitoring impacts emerging as a result of variation will be important, to identify best practice and minimise any negative implications.

Recommendations for Macmillan

For the remainder of the MICCP, Macmillan could work with CUHFT to:

Recommendation 12: Consider how best to engage local GPs. Workstream 4 was de-prioritised due to competing demands on the MICCP team and wider system. However, given the progress and successes achieved to date, it feels timely to intensify the efforts to engage GPs in the process. This will help to ensure they are ready for Treatment Summaries to be introduced more widely, and are sufficiently knowledgeable about the Recovery Package. One possible approach may be to use the Macmillan GP's networks and expertise for support with communicating key messages to GPs and securing buy in. Phased implementation, targeting GPs in certain localities before a wider roll out, may help to ensure the task is manageable and generate a pool of GP advocates for the approach, to help secure the buy in of their peers.

Recommendation 13: Continue to maintain and strengthen relationships with CCGs and the STP. This will help to build understanding of (and inform) their priorities for future commissioning. Key areas of focus might be to:

- Continue to raise awareness of how the increase in demand for cancer care is likely to absorb any capacity and economic impacts realised through risk stratification activity
- Continue to manage expectations around the economic impacts of the Recovery Package and how the benefits of improved capacity to self-manage are likely to be realised in the longer term only
- Understand more about the reasoning behind Cancer Alliance targets and manage expectations around limitations in the current dataset/reporting tools.

Recommendation 14: Continue to share learning emerging from elsewhere regarding the Recovery Package or components of the MICCP (e.g. eHNA, Treatment Summaries etc.). Learning from implementation of Recovery Package elements elsewhere, for example, South Yorkshire, may usefully inform refinement of the model in Addenbrooke's, and/or inform the rollout to other sites.

Recommendation 15: Consider delivering Health and Wellbeing events at a regional level, rather than events being delivered by the Trust. Learning from the Health and Wellbeing events reveals that these are resource intensive to deliver and require extensive management by a large steering group in order to align different partner priorities, meaning that they are difficult to resource at Trust level. There may be economies of scale through a regional approach, which Macmillan could usefully play a key role in.

Recommendation 16: Consider practical implications of tool changes and implementation. The administration of the eHNA was complicated by the introduction of new Macmillan administration steps. In future it may be of use to work with Trusts before introducing IT changes which affect day to day operational activities, possibly trialling new ways of working in real-world settings before roll-out.



Recommendations for others seeking to replicate the MICCP model

Whilst acknowledging that contextual factors acted as both barriers and enablers to successful implementation, below we provide some recommendations for others seeking to integrate cancer care in their locality.

Planning activity and prioritising key areas

Recommendation A: Ensure resource requirements have been thought through. Resourcing a dedicated programme team with the necessary capacity and capability to undertake a wide range of activities, from strategic engagement and influencing, to mentoring and administrative support, is key. This is likely to require administrative as well as project management and leadership capacity, dedicated to the programme to limit the impact of competing demands.

Alongside a dedicated team resource, it is important to consider wider resource implications. For example:

- Whether any new technology is required (for example, iPads to enable eHNA implementation on site)
- Whether any externally provided training is required, and at what scale/level
- The materials available to address the needs and concerns identified by PABC and their family and friends for example, information leaflets and/or services to refer in to (e.g. Exercise Referral schemes or counselling services).

Recommendation B: Explore IT, information governance and monitoring requirements at an early stage, and secure buy-in from the IT support team (and others). IT requirements are context specific, but it may be necessary to build systems to support information transfer and extraction. Consider the practicalities around the electronic transfer of eHNA records, Care Plans, Treatment Summaries and support referrals, including information sharing arrangements and the IT system requirements. In addition, agree at the outset, as far as possible, exactly what monitoring data is required to meet commissioner needs. Once the 'need' has been identified, establish whether existing systems can be amended to meet the needs, or whether new builds are required; a work plan and realistic timeline will then be needed to manage stakeholder expectations and align development with other programme activities.

Recommendation C: Focus early activity on 'winnable' sites and activities. These are likely to be those cancer sites with the capacity, capability and physical space to conduct risk stratification activities and embed the Recovery Package. Starting small and achieving quick wins can help to generate enthusiasm, momentum and learning to support wider roll out. Sites which have already begun risk stratified activities, or those with clinical champions who can generate buy-in amongst others, may offer the quickest potential wins.

Recommendation D: Be mindful that risk stratification can be a long process and that external factors may adversely affect progress or momentum. It is vital to manage expectations and be realistic about the anticipated pace of change, building in contingencies where needed. Linked to this, be realistic about the scale and range of impacts expected during pilot timeframes; identifying proxy outcomes or interim successes can prove vital in this respect.



Recommendation E: Build in evaluation and PABC engagement at the outset. Collect meaningful qualitative and quantitative PABC experience data where appropriate e.g. gathering risk stratified clinic feedback, and use this in a structured way to inform revisions and refinement to the model. In addition, co-producing patient-facing elements of the model, for example, the eHNA completion processes and any experiential data collection tools, can help to ensure they are user-friendly and appropriate.

Strategic buy in and planning for sustainability

Recommendation F: Align integration with the wider Cancer Alliance and national cancer strategy. Ensuring strategic alignment will be key to securing funding and buy in. Engaging senior champions to position integration as an integral part of local strategy may also help with the profile of the programme and ensure implementation is prioritised. Present the costs of 'doing nothing' alongside the positive impacts expected.

Recommendation G: Gain broader 'on the ground' awareness by identifying and supporting clinical champions who can influence and persuade colleagues to engage. Clinical champions can prove key in securing buy in amongst their colleagues – they can offer the credibility and contextual understanding needed to generate enthusiasm amongst busy frontline practitioners. Clinical champions might usefully be recruited at both clinical lead and frontline practitioner levels, to engage different levels of the cancer workforce.

Recommendation H: Plan for sustainability at the outset. This is vital to avoid the new ways of working as being seen as 'just another initiative' and to help overcome any change fatigue. Engaging with commissioners will be vital to supporting sustainability; understanding and meeting their evidence needs is key.

Training, development and culture change

Recommendation I: Link Recovery Package and risk stratification activities into staff development plans. For example, the use of eHNA or Care Plans, and/or attending training. This can all contribute towards culture change and sustaining the impacts of the model and new ways of working. Alongside this, consider building relevant training into induction programmes for new joiners to the cancer workforce – staff and volunteers.

Recommendation J: Implement a tailored learning and development programme alongside the new care pathways. This should seek to embed the new ways of working, focusing on building a trusting, open relationship between PABC and the cancer workforce, encouraging culture change. Targeting the early implementers of the model for the first waves of training may help to ensure the ways of working align with the new pathways.



11. Acknowledgements

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